

**WRITTEN CANCER NARRATIVES**  
**AN ETHNOMEDICAL STUDY OF CANCER PATIENTS' THOUGHTS,**  
**EMOTIONS AND EXPERIENCES**

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**Written Cancer Narratives**  
An Ethnomedical Study of Cancer Patients' Thoughts, Emotions and  
Experiences

Academic dissertation to be publicly discussed, by due permission of the Faculty of Arts  
at the University of Helsinki in Arppeanum lecture-hall (Helsinki University Museum), on  
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# Contents

Contents.....	3
Acknowledgements .....	6
Introduction .....	7
1 Cancer Patients' Writing and the Process of Selecting Research Materials .....	13
The premises and goals of the research .....	15
The <i>Kun sairastuin syöpään</i> (when I fell ill with cancer) writing competition .....	19
Becoming familiar with resources .....	22
Sources providing context: letters, ethnomedical records and Internet forums.....	36
Approaching reliable results .....	42
Selecting materials for further discussion .....	47
Problems with the presentation of the research results.....	49
Evaluation of the available sources .....	52
2 Cancer Narratives as Ethnographic Sources.....	56
The motivation to write .....	57
Inner narrative .....	61
The cancer narrative as a key narrative.....	64
Remembering and memory .....	66
Detecting 'meaningful silence' .....	69
The personal voice and culturally bound representations.....	70
The status of written cancer narratives.....	72
Cancer narrative as a thematic whole .....	75
Conclusions .....	76
3 Cancer in Finnish Folk Medicine .....	78
The problem of recognising cancer among archive sources .....	79
Cancer's ethnonyms .....	82
The problems associated with defining cancer aetiology .....	85
Some notions about the medical discourse of the time .....	87
Treating 'the growth' and 'the eater' .....	92
Gaining healing power .....	98
Conclusions .....	102

4	The Cancer Narrative as Dialogic Imagination .....	104
	The text selection criteria .....	106
	Seth's story: <i>Muutamia haja-ajatuksia ja muistoja syövästä</i> (Some indistinct ideas and reminiscences on cancer). ....	108
	Hanna's story: <i>Mitä ajattelinkaan ennen kuin sairastuin syöpään?</i> (What did I think before I fell ill with cancer?) .....	114
	Ruth's story: <i>Melanooma ja minä</i> (Melanoma and I).....	119
	Meaningful 'knots' of time .....	123
	Meaningful 'knots' of place .....	129
	The diversity of voices .....	131
	'Voicing' and the status of the author .....	134
	Conclusions .....	136
5	Popular Images of Cancer in Modern Discourse .....	138
	The problematic concept of cancer .....	140
	Common problems associated with recognising cancer .....	143
	Popular cancer aetiology .....	148
	Natural external and internal causes.....	152
	Psychological and behaviouristic causes: downtrodden women and 'go-getter' men ....	158
	The vulnerable position of the cancer patient .....	164
	Conclusions .....	168
6	The Moment of Diagnosis and Metaphoric Transformation .....	170
	The moment of diagnosis and subsequent expression of emotion in writing .....	171
	Metaphors in health and illness discourse .....	174
	The meaning of metaphors.....	177
	The interpretation of metaphors as "works in miniature" .....	180
	Metaphor as a culture-bound key to inner feelings.....	186
	Conclusions .....	189
7	Patients' Feelings About Deficiencies in the Biomedical Healing Drama.....	190
	Towards modern healthcare institutions .....	191
	Passive and patient .....	194
	Patients' experiences in healthcare institutions .....	196
	Physical change and its importance to the patient while in hospital.....	202
	Silent doctors .....	205
	The power of healing narratives .....	209
	Conclusions .....	213
8	Methods of Coping and Alternative or Complementary Self-Help .....	215

Arguments regarding the need for self-help .....	216
Complementary treatments in use.....	223
Biologically-based practices .....	225
Mind-body medicine .....	227
Energy medicine .....	230
Basic concerns and problems with using complementary treatments .....	233
Conclusions .....	236
9    Dream Narratives and How They Frame the Cancer Experience.....	238
Dreams and dream-like images as events .....	239
Making connections.....	243
Cancer patients' dreams and dream-like images .....	245
Interpreted imagery in the cancer narratives .....	247
Dream narratives as paths for the expression of suppressed emotions and marginal themes .....	251
The individual and cultural meaning of dreams .....	252
Conclusions .....	254
10    The Study of Written Cancer Narratives: Comments and Conclusions.....	256
The historical development of popular cancer discourse.....	257
Individual interpretations within linguistic and cultural frameworks .....	260
Representations or reconstructions of lived experiences .....	261
Practical structuralism and evocative milieux as factors impacting on the archival request .....	263
Patients' feelings and suppressed ideas revealed in metaphors and dreams .....	265
Bibliography .....	268
Internet sources.....	283
Archive Sources.....	285
Appendix 1 .....	300
Appendix 2 .....	302
Seth's story: Some indistinct ideas and reminiscences on cancer .....	302
Hanna's story: What did I think before I fell ill with cancer? .....	306
Ruth's story: Melanoma and I.....	309

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## Introduction

Cancer is a serious health challenge in Finland. Today every fourth person is expected to fall ill with cancer at some stage of his or her life. Although cancer is not a new illness in humanity's history, during the past decades the number of cancer patients has grown radically, partly because of changing lifestyles but also because of environmental problems and work conditions. The rise in the rates of cancer diagnosis is also explainable because diagnosis techniques have become more advanced and the state has begun to support regular check-ups and follow-ups for certain risk groups. Nevertheless, what exactly the reasons are for contracting cancer is still unclear. This lack of clarity regarding cancer's origin certainly affects the popular understanding of the disease. Accordingly, cancer narratives present a fascinating mixture of ideas deriving from scientific discoveries, popular knowledge and personal experience.

Above all, cancer narratives demonstrate that having cancer in many ways changes an individual's life. The culturally determined transformation from an ordinary, or normal, person into a cancer patient, forces people to re-negotiate their self image, their understanding of life and their place in the everyday milieu. Cancer narratives show that the word cancer causes fear and confusion, and evokes an image of painful and inescapable death. The various social misjudgements are one of the greatest challenges to all cancer patients. Therefore, people must carefully choose how, when and with whom they share their cancer experience. Considering this situation, written cancer narratives function as mediators of individual thought, experience and emotions relating to cancer. In addition, these texts form a good source from which to study the representations of culture-bound ideas regarding cancer in various contexts. Accordingly, cancer narratives form an excellent source for the examination of the individual and cultural aspects of this particular illness, whereas for cancer patients, composing a cancer narrative may become a path by which to regain the *self*.

The ideas for studies often emerge from interaction between a researcher's substantive interests, intimate knowledge, and the information contained in the research materials. Above all, the general selection of research topic for this thesis is based on my personal interest in narration and narrating where it concerns illness experience. Naturally, this particular interest has its history. When I turned twenty my mother was diagnosed with

cancer. From this dreadful time I recall only one overwhelming thought – my mother is going to die. The image of death was inseparably connected to the word ‘cancer’ in my mind. Because of this image, I could not believe that my mother would be well again. As a matter of fact, the only thing I knew about cancer was that everyone having it was going to die soon. My fear was so great that I never discussed it with my mother or anyone else in my family. I was able to share this thought only with my best friend, who had already lost her mother to cancer at the age of six.

The years passed and my mother was still with us. However, her depression and fear of a reoccurrence of her cancer raised multiple questions in me. I could not understand why it was so difficult to accept being healthy again when the cancer had officially been cured. I could not understand why my mother continued to be depressed, worried and suspicious about any minor bodily concern. I could not understand why she did not let go and continue living as she had done before her illness. I could not understand what had changed in her life and how, and was it all because of cancer?

As a folklore student at the University of Tartu, Estonia, I became interested in folk belief, narration and folk medicine. I worked with folk images of *ague* (malaria), at first in Estonia, and also since 1999, in Finland (Paal 2004). The materials on *ague*, preserved in the archives, were interesting and appealing, however, various questions came to trouble me during my research. I was not sure how well I could interpret *ague*-related texts, or whether an interpretation was possible at all without having access to the thoughts and feelings of the people who composed these stories. I was not sure what the meaning of *ague* was in rural society or what the true aim of the belief legends that talked about this folk illness was. All I understood was that finding answers to these questions was complicated, since the tradition has gone together with its carriers and there was no context that could extend my awareness. I realised that no medical history book can tell me about the inner thoughts and feelings of people who suffered from the *ague* at the beginning of the 19th century, and thus, no archive text could help me understand individual considerations relating to the illness experience.

In spring 2003 I found a text in the Finnish Folklore Archive about healing the *ague*. The text talked about a woman who, during the healing process, was pulled through a coffin in a graveyard. Although she got rid of the *ague*, a nail inside the coffin scratched her and caused a new illness, which was called *ruumiin koi* (body moth). I grasped for an ethnographical dictionary, which revealed that the ‘body moth’ was a name for cancer in



Finnish folk medicine. From that moment on, I knew what my next research topic was going to be. It was going to be cancer and its representations in folk narratives.

I was pleasantly surprised when I discovered that in 1994 the Finnish Folklore Archive and cancer patients' support establishments had arranged a writing competition entitled *Kun sairastuin syöpään* (when I fell ill with cancer). In the context of the writing competition the respondents were encouraged to share their emotions, feelings, and thoughts concerning their cancer experiences. For me, discovering this material, containing 6 000 pages of written cancer narratives from 672 respondents, meant that I was given an opportunity to examine, and hopefully also understand, what was going on when a person becomes ill with cancer.

Over the past years I have read numerous studies dealing with illnesses and their representations in narrative. Perhaps the most inspiring book for me was *Once Upon a Virus* (2004) by Diane E. Goldstein. Goldstein's study deals with AIDS legends, analysing the meaning and the position of narratives in the everyday context. She has proposed that texts communicating vernacular health issues "are not just entertaining titbits of dinner conversation but rather the incredibly powerful core of personal and collective action" (Goldstein 2004, 157). Goldstein argues that people are not slaves to the stories they hear, meaning that we do not think that told narratives are the supreme truth. However, the narratives about illnesses unite culture and understanding and contain the representations of health truths that influence people's health choices and arguments in everyday life. The truths and views that become represented as individual interpretations in such narratives represent the particular discourse influenced by language (ideologies) and culture framed by the institutional arrangement of a particular society.

The narrative approach in this thesis is based on the idea that narrating and narratives act as a 'root metaphor' for many different aspects of human life (Mattingly 1998, 86). In case of illness the narrative concentrates on the illness process, particularly on the moment of diagnosis, pathological drama, and the final outcome – recovery or death (Sacks 2007, ix–x). The moment of diagnosis causes a transformation that marks a turn in an individual life. The pathological drama represents the healing ritual (treatments) that is applied to cure the illness and return to normal life. Despite all human efforts the final outcome is uncertain in cases of cancer. More importantly, the individual experience is also in many ways different from the culture-bound expectations people have as they receive their cancer diagnoses. The narrative approach makes it possible to study human reasoning,

emotions and experience in an everyday context as well as considering significant events in a particular culturally defined context.

The thesis is organised as a series of analyses dealing with representations of the cancer experience and their significance in the particular context. The thesis follows the general course of illness from the moment of diagnosis until the final solution to the individual cancer experience. In this work I analyse various extended primary and secondary narratives as segments of self-expression in order to present the respondents' thoughts, feeling and experiences relating to their illness experience. By doing so I shall point out the particular tendencies characteristic to cancer narratives. Because of the uniqueness of every cancer experience the cancer narratives are also unique in many ways, although they all follow the course of the illness. This also highlights the main difference between the experiences gained, and those presented in the writing: in cancer narratives the illness experience supplies the narrative structure with temporal and spatial meeting points that make the narrative comprehensible and meaningful.

In the first chapter I introduce the research aims and materials. I suggest that those interested in cancer experience representations continue reading from Chapter 3, as the most significant methodological issues are repeated at the beginning of each chapter. However, the detailed overview of the research material is significant to understanding the values of the analysed source material. By raising methodological issues in the first chapter, I aim to highlight the possibilities present when analysing thematic narratives within the folklore paradigm.

Chapter 2 examines the written cancer narratives, pointing out the significance of writing down the illness experience as a method for coping with, and analysing, one's illness process. Above all it is the need to discuss one's illness that makes people compose illness narratives. Although the motivations and styles are different, in their writing people express many important individual and culture-bound factors dealing with the period of their cancer. Although general expectations towards written narratives proceed from the image of narrative as a meaningful, coherent and finalised method of self-expression, the cancer narratives collected via the writing competition prove to be different in many ways.

Chapter 3 analyses folk medical records originating from the Finnish Folklore Archive. This part of the thesis introduces the significance of cancer in Finnish folk medicine. It describes folk medical images of cancer's origin as well as its cures and treatments. The aim of this diachronic insight is to point out the development of cancer's significance – alongside discoveries in modern medicine – into a serious health problem.

Chapter 4 analyses three cancer narratives as thematic wholes. The central goal of this chapter is to compare three narratives in order to draw out the important similarities and differences between these representations of the illness experience. It analyses the structure of the cancer narratives and the characteristic spatio-temporal ‘knots’ that are used to mediate the meaning. It also concentrates on the authorial ‘voicing’ used to express individual, culture-bound and societal aspects of the cancer experience in different milieux. In this chapter, cancer patients’ narratives are approached as wholes built on dialogic imagination.

Chapter 5 introduces the cultural stigma surrounding cancer as an illness and as an experience. Discussion in this chapter of culture-bound attitudes towards the illness from an ethnomedical point of view aims to highlight the particular nature of cancer as a modern mythological illness, which in many ways stigmatises the illness carrier.

Chapter 6 focuses on the moment of diagnosis. This moment is represented in the cancer narratives as emotionally the most difficult moment during the illness process. In their writing, respondents use various metaphors to express their emotions at that particular time. These metaphors may be approached as miniature works that represent the transformation from an ordinary person into a – stigmatised – cancer patient. On the other hand, metaphors also work as ‘culturally bound keys’ to emotions and therefore should not be overlooked, even within these thematic narratives.

Chapter 7 discusses the situation of cancer patients as they encounter the ‘rites of passage’ that society offers them in order that they become well again. The time spent in hospital is described not only as a time of bodily alteration, but also as representing a period of time in which there is a ‘looseness’ of self. This feeling of looseness is a result of entering a new social setting, a temporary community of sufferers. Daily life in healthcare institutions follows its own rules and people governed by these rules feel themselves insignificant as individuals. This chapter emphasises the patient’s need for the human touch, which may be established through communication with other patients. In particular, narratives written during the healing process become significant and offer the opportunity of analysing and reinterpreting the situation as the years go by.

Chapter 8 continues to examine the methods of identity alteration used to find self-help strategies. This chapter studies the use of complementary and alternative self-help methods among Finnish cancer patients. The lack of patient-doctor communication prompts patients to search for alternative paths to recovery. Cancer patients claim that making such decisions creates even more stress and fear, as people are very loyal to the treatments

offered by evidence-based medicine, and at the same time doctors refuse to discuss other opportunities. Thus, patients struggle to use complementary self-help methods in secret, which is an interesting ethnographic phenomenon, although in everyday life this struggle increases the amount of psychological and bodily suffering.

Chapter 9 demonstrates another opportunity to communicate emotionally complex issues and suppressed ideas concerning the individual illness experience. It seems natural that people discuss their dreams and dream-like feelings, even if they are connected to illnesses or even death. Dream events become interpreted in terms of waking experience and become in themselves significant narratives connected to the illness experience. Such meaningful narratives remain significant even years later and become good tools by which to mediate the fear and confusion that surround the illness process.

Above all, this work is about patients and their points of view. It concentrates on patients' 'voicings', which are important in order to make the cancer experience understandable and 'open' in the current cultural and societal setting. When following this thesis one should bear in mind that it is the work of a folklorist who is specialised in illness narratives and traditional traits occurring in narrative representations. Particularly in the written narratives, the natural world and the glimpses of tradition become bound together with one general aim – to tackle the illness and mediate its meanings.

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# **1 Cancer Patients' Writing and the Process of Selecting Research Materials**

Finnish folklorists have, since the 19th century, enlisted the help of ordinary people with writing skills in order to collect and preserve various kinds of folk tradition. This kind of collecting of popular ideas on various topics is not very common in other countries, but in Finland the long tradition of organising various writing competitions in order to collect autobiographical reminiscences on a variety of sociocultural topics began in the 1930s and has continued ever since (Fingerroos & Peltonen 2006, 14–17, Latvala 2005, 24–33, Salmi-Niklander 2004, 37–38, Virtanen 1988, 47). Various calls for writing, mostly lead by open-ended questions, are therefore familiar to Finns and thus such competitions result in numerous responses from people describing their individual experiences via the medium of thematic writing.

The motivations for participating in such competitions vary from the participants' needs to share their individual experiences, to a pragmatic desire to win a prize. Traditionally, the best writing has been rewarded by the organising committees and the winners have received for compensation either money or books. Thus, it is not uncommon for participants to append their bank account numbers to their entries, whereas in case of cancer, perhaps because of this illnesses image in the particular cultural setting, the desire to win the prize has not led to the creation of imaginary stories and experiences.

Quite typically, among the respondents are many people with broken souls who find themselves in life crises trying to organise their lives through writing (Pöysä 1997, 48–49). Indeed, illness, and in particular falling ill with cancer, may be seen as a life crisis that forces people to reconsider their lives, and in this context writing functions as a therapeutic treatment (Bolton 1999, 13). When analysing the Finnish lumberjack tradition, Jyrki Pöysä has pointed out that for some respondents the writing competitions becomes a path to explore their marginal position within society (Pöysä 1997, 49). For cancer patients, writing appears to be characteristic of the desire to represent the cancer experience in a more positive light and to reduce this marginal image (Couser 1997, 182), both as a response to the generally accepted ideas that having cancer is a *kärsimysnäytelmä* (passion), *hidas kuoleminen* (slow death) or *kuihtuminen* (shrinking). Most important, and separate from the various individual reasons for participating, is the fact that the great number of participants, along with the large number of responses, proves that the

possibility to discuss and represent the cancer experience has been generally welcomed among the target group.

Illness narratives, autobiographical and biographical accounts of illness, are also known as (auto)pathographies. The term pathographies was coined in 1993 by Anne Hunsaker Hawkins in her book *Reconstructing Illness: Studies in Pathography* (Hawkins 1999). With this book a new literary genre was declared, which has since become the target for many scholars, mainly from the medical and sociological field. Rita Charon has called this approach a "new frame" for medicine, which should improve many of the insufficiencies in today's medical care (Charon 2006, 6–10). Namely, the narrative-based studies shed light on patients' experiences, their fears, health beliefs, individual expectations and disappointments within modern medical discourse. Bringing the patient's point of view - often suppressed in the biomedical context - into the light can thus be interpreted as a form of social control (Frank 1995, 97). The cancer narratives presented in this work have many aspects in common with pathographies or book-length illness stories; however, as these materials have been collected via archival request, their main value lays in their ethnographic point of view, which concentrates on describing an individual pathological drama and not so much on presenting the various autobiographical aspects that are more characteristic to pathographies (Hawkins 1999, 25–30). Thus, this thesis is an attempt to add an ethnographic value to patients' writing. Cancer patients' narratives, which could be seen as short pathographies from the generic point of view, present illness and its written representation as culturally and ideologically pre-defined discourse influenced by various diachronic and synchronic developments.

With the long tradition of collecting thematic writing in Finland in mind, the folklorist Satu Apo has argued that thematic writing, as a manner of traditional self-expression, may be well accepted for folklore research (Apo 1995, 179). Until the 1980s, thematic writing was not seen as a suitable source for folklore studies in Finland. The main problem was that there was no suitable classification for this material, as the existing classifications were based on earlier research paradigms concerned with fairy tales and Kalevala metric poetry (Latvala 2005, 27). In the 1970s Finnish anthropologists and sociologists became more interested in autobiographies, and a decade later folklorists found a way to study the written (life) narratives that had been sent to the folklore archives (Fingerroos & Kurki 2008, 11–14, Fingerroos & Haanpää 2006, 26–30). Folklorists have come to the conclusion that life narratives dealing with different topics share people's individual ideas and cultural

values and create a significant meeting point in the form of a culturally understandable narrative (Hatakka 2004, 172–173).

However, accepting thematic writing like this as suitable for study by folklorists did not solve the multiple problems connected with named sources. Like any other folkloristic source the various collected thematic writing has both positive and negative aspects, which one should be aware of when utilising these materials. Therefore, in the following pages, after presenting the main premises and research goals of the thesis, I introduce the general aims of data collection, observe the results of the writing competitions and argue about the main problems concerned with the interpretation of thematic narratives.

## **The premises and goals of the research**

My primary intention is to examine cancer narrative from the folkloristic point of view in order to find and compare popular ideas regarding cancer, both in the past and today. In general, the folkloristic approach refers to the study of people's attitudes and behaviour towards certain culture-bound traditions, and in this work the aim is to study cancer and its significance and images in the Finnish context. I analyse written cancer narratives by following the course of the pathological drama in order to point out what it means to fall ill with cancer and how this life-threatening experience is perceived and expressed in written text.

Above all, the experience-based narratives dealing with cancer are approached as ethnographic sources that express patients' inner feelings and attitudes, both to being ill and to becoming well again. To approach cancer patients' ideas and reasoning in order to interpret them correctly, I use multiple perspectives (see Chapter 2). This also means that I approach cancer patients' writing as containing thematic units, with certain beginnings and endings, characterising the illness course. At the same time I point out that such units consist of various segments of self-expression, such as descriptions of various milieux or primary narratives with different aims.

In addition to a narrative approach, the following study is ethnomedical, uniting popular health beliefs that derive from Finnish folk medicine, as well as those connected with alternative medicine and with the field of biomedicine dominant in the contemporary cultural context. Naturally, these fields contain their characteristic features. The concept of 'folk medicine' refers to understandings of health and illness that are based on a particular

belief system. 'Alternative medicine' represents methods and therapies that derive from different times, cultures and traditions that have been adopted in a new cultural context. 'Biomedicine' is used to indicate the purely scientific, so-called evidence-based, medicine dominant in Finnish state-supported healthcare centres. In Finland, the concepts of folk medicine and alternative medicine have often been interpreted as the same phenomenon: something that is in some form of opposition to biomedicine (Honko 1983, 34). Based on the studied narratives, and considering the ethnomedical approach, making such an opposition is meaningless. Cancer narratives demonstrate that even those who agree with public opinion - that compared to biomedicine, folk medicine and alternative medicine are useless hocus-pocus - employ in their writing popular ideas and beliefs that are mediated by language. Thus, such ideas and beliefs are culture specific, and therefore, according to my interpretation, have an ethnomedical character. I shall examine the human reasoning surrounding these contexts, because as the cancer narratives point out, in cases of illness individuals' abilities to think and argue becomes the dominant weapon that helps them through challenging times.

With this study I wish to draw the reader's attention to cancer's meaning in Finnish culture from the cancer patient's point of view. I begin by introducing cancer and its position before modernisation by using ethnomedical records. The comparison between older sources and the cancer narratives allows the suggestion that even today cancer may be approached as a modern mythological illness. People fear cancer as they fear AIDS, and quite typically it is connected with images of death and dying. Interestingly enough, despite its mythical image cancer has not become a topic for vivid stories and legends, as has AIDS (Goldstein 2004, 13–14). Rather, discussing and sharing the cancer experience has been interpreted as stigmatising and is thus obscured by significant silence (see Chapter 2). The still unexplained nature of cancer's origin is reflected in today's cancer prevention methods and in popular beliefs concerning its origin. For most people, it is difficult to grasp the biomedical definition of cancer as being the result of a single cell mutation; it is far easier to imagine it as an outside 'intruder', 'set-off' by an individual's nature or behaviour (see Chapter 5). The roots of such explanations lay in the history of medicine.

My study shows that for a long time cancer was diagnosable only visibly and manually. Typically, cancer was discovered in its late stages, occurring as an open wound or incurable lump in the body. Since medical discoveries and the development of new techniques, cancer has also become diagnosable in its early stages. This has led to a



situation in which the cancer diagnosis may come as an unpleasant and, foremost, unexpected surprise before any ‘normal’ signs of illness, such as tiredness, fever or pain, have begun to disrupt the individual’s daily activities. In such situations, the difference between being healthy and being ill is determined by modern medicine and not by the individual.

The available modern medical treatments, perhaps excluding surgical procedures, remain close to the peculiar healing methods offered in folk medicine a century ago. The main idea behind treatment has again radically changed. Folk medical healing aimed to balance a sick person’s condition, either by the power of words or with different healing medicines and treatments. Biomedical treatments aim to destroy the mutant cells or stop their activities. The cancer narratives show that the primary idea of Hippocratic medicine, *primum non nocere*, often translated as ‘first do no harm’, is long abandoned in today’s medicine. Or put in other words, treatments make people truly ill and make them suffer: *Koin jatkohoidot vaikeampana kuin itse syöpädiagnoosin ja leikkauksen.* “The treatments that I got afterwards were for me harder to accept than the cancer diagnosis or the surgery.” (549) *“Tunsin itseni terveeksi niin kauan, kunnes tehtiin radikaalileikkaus ja annettiin sädehoitoa. Silloin vasta aloin olla sairas, väsynyt muutaman vuoden.* “I felt myself healthy until the radical surgery and X-ray treatments. Then I became really ill, tired for many years.” (555) This is a really interesting situation from the ethnomedical point of view. The main criticism that biomedicine makes of other treatment types is that any treatment used to complement biomedical cures cause more harm than good. In pointing out this problem, I do not wish to justify or accuse, only to discuss. Analysing the cancer narratives from the ethnomedical viewpoint is an attempt to present patients’ needs as well as their desire that at some point they again be treated and approached as individuals, people who are able to make decisions and, in collaboration with doctors, improve their own health.

In terms of generic finalisation, the structure of the cancer narrative is somewhat loose. However, despite this structural looseness, the culture-bound and socially supported expectations arising from popular belief become easily visible among the themes tackled within the texts studied here.

The thesis goes back and forth between the form and content of the writing competition narratives, using historical and societal insights to outline how cancer discourse is mediated by language and culture. The structural-descriptive examination of different segments in the cancer narratives is compiled in order to discover the culturally defined

meaning within, but it also goes beyond these texts, which in everyday life influence individual reasoning, and which, in the current context have, to some extent, affected the process of written self-expression. This study of the interrelations between the external and internal aspects of the narratives is inspired by William Hanks' suggestion that "utterances are part of social projects, not merely vehicles for expressing thoughts" (Hanks 1996, 168). As a matter of fact, Hanks' statement has become a central argument for the narrative analysis presented in this work. To be aware of what is expressed we must examine how it is expressed and why a particular speech situation is given as it appears. In my opinion, questions, particularly how and why, help us to comprehend the individual's situation and create the opportunity to find answers to the most exciting question: What is going on? The need to understand has guided me throughout the process of studying and examining the available sources.

While becoming acquainted with the research materials, I approached the cancer narratives as a resource that creates an intertextual universe in which single texts composed by different authors begin to communicate with each other. By doing so, I am inspired by the view of American linguist Walter J. Ong, who has suggested that any written text, once finished, becomes removed from its author, creating an independent discourse (Ong 2002, 80). Although I am aware that the experiences, thoughts, and feelings uttered in the cancer narratives are the result of each author's cognition, interpretation, and verbalisation, in writing, these 'phases' become united, 'fixed' in a form of written text that created an autonomic discourse. Such autonomic discourse offers for the researcher an endless number of opportunities to examine and study the texts without including the author, with the text becoming the only source posing questions and providing answers. My attempt to exclude the authors fails because of my interest in the 'intended' aspects of these cancer narratives. Mikhael Bakhtin's suggestion that all narratives have a "responsive" character (Bakhtin 1981, 280) makes me look for segments in which the respondents (indirectly) communicate with different people and institutions, and also milieux, in order to express their various concerns regarding their illness experience.

Somewhat to my surprise, meaningful images relating to cancer occur in single words, metaphoric expressions, dream narratives and sometimes even in the intended silences within - or even beyond - the source materials. Cancer patients' thoughts, emotions, and experiences represented in written texts point out various connections between the form and the content mediating the meaning. Accordingly, instead of being purely ethnomedical, this study turns into a multi-level analysis of cancer discourse. It is worth emphasising that

most of the topics handled in the cancer narratives can be described as spontaneous input within the narratives. I refer to the fact that the way respondents handle the concept of cancer, express their feelings on hearing the cancer diagnosis, analyse the reasons for falling ill, share their dreams, or chose to be silent, has nothing to do with the instructions given by the organisers of the writing competition. I am quite convinced that only the large number of available texts gives the possibility to identify and focus on the somewhat unexpected aspects that occur.

The analysis of the temporal and spatial meeting points in the structural segments of the narratives demonstrates that the secondary narratives concentrate mainly on the pathological drama, briefly referring to the times before the illness was diagnosed and concluding with reference to life after treatment. In a similar way, to coincide with readers' expectations, the chapters in the thesis are organised to follow the culturally and socially acknowledged process of having cancer. This means presenting cancer from the moment of diagnosis up to the end of the experience, which, contrary to cultural expectation, is not necessarily a painful death. As many respondents to the writing competition do, I want to point out that for many cancer patients 'the end' (although it is difficult to define it accurately) of the cancer experience actually marks the beginning of a somewhat different life.

Before moving further, I wish once more to underline that the ideas and results that will be presented in this work are different from those presented in medical or sociological studies. The evidence in this work is the written narrative, and the conclusions are based on the intertextual discourse created by different writing. As I see it, the available material communicating the individual, collective and societal aspects of cancer at the same time defines the possible results. Through significant words, expressions, themes, and narrated events respondents expressed various issues relating to cancer. Thus, I observe the significance of cancer via multiple cancer-concerned events connected with different times and places.

## **The *Kun sairastuin syöpään* (when I fell ill with cancer) writing competition**

The *Kun sairastuin syöpään* (when I fell ill with cancer) writing competition was announced on the 1st of May 1994 and lasted until the 30<sup>th</sup> of September 1994. The writing

competition was organised by *Suomen Syöpäpotilaat ry* (the Finnish Cancer Patients' Association), *Suomen Syöpäyhdistys ry* (the Finnish Cancer Union), and *Suomalaisen Kirjallisuuden Seuran kansanrunousarkisto* (the Folklore Archive of the Finnish Literary Society). The main idea, as printed on the writing competition leaflet, was as follows (see original in Appendix 1):

Falling ill with a long-term or serious illness may change a person, as well as his or her daily life, in many ways. Fears relating to cancer also cause concern for the patient's friends and relatives. In order to survive, patients find that talking with other patients, sharing personal experiences relating to falling ill and living with an illness, proves useful. Writing down personal experiences may also be helpful in order to make clear one's ideas about illness and its influences on oneself and the surrounding environment.

The organisers pointed out their hope for personal and authentic results. All participants were asked to describe their experiences, thoughts and feelings as accurately as possible. Also the main aim of the writing competition was clearly stated:

The Finnish Cancer Patients' Association wishes to collect experiences and thoughts personally narrated by cancer patients. The idea is to select the best writing in order to make a book that will allow cancer patients and their relatives to share their ways of surviving the problems caused by the illness. Relatives and close friends are also welcome to participate in the writing competition. The writer may select a suitable heading for his or her writing.

In the competition proposal, the organisers asked the respondents to discuss the following themes:

- Tell us about the experiences and feelings caused by your cancer, as you experienced them.
- Explain how falling ill influenced your relationships with other people. How did family members, friends and work colleagues take your illness?
- Has the illness changed your self-image? If yes, explain how.
- Were you able to talk about your illness with others? Did you want to do so?
- How did you survive the crisis caused by illness?
- Who supported you? Who made you suffer the most? Why so?
- Explain how people at the hospital acted towards you as a person and a patient. Did you feel safe and did you get enough support and information?

- Will time heal? Do you hope that in time you will be able to adapt? Will life continue as it was before falling ill?
- How did you survive your illness?

Additionally, the organisers of the writing competition asked people to write down their name, profession, educational background, date and place of birth, current address and phone number. Or respondents could use a nickname if they wished. Respondents were asked if the writing, or parts of it, could be published if the personal data was changed. The entries were expected to be less than 50 pages long, written on one side of A4 paper with plenty of space on the left margin. Organisers also told respondents that the writing would not be returned, so they should make a copy.

People were encouraged to present personal experiences in a creative manner. For the winner, the organising committee offered 3 000 Finnish Marks, for second place 2 000 and for third 1 000 (1 EURO = 6 FIM). Additionally, five prizes of 500 Marks would be given to other randomly selected participants. The five members of the board deciding the winners consisted of a school rector, the chair of the literature archive, a medical doctor, a manager from the cancer association and a physiotherapist. The results were made public in November 1994. A book titled *Haaste elämältä: kokemuksia syövästä* (The Challenge of Life: The Cancer Experience), published in 1996 and edited by Päivi Hietanen and Juha Nirkko, contained a selection of the best writing with comments from experts.

The importance of carefully studying the instructions given to writers is central in understanding the aims of both the collectors and the participants. Although the first impression when reading the responses seems to be that people were rather independent of the questions posed, further examination shows that people were well aware of the organisers' expectations. In cases where the respondents followed their own personal and authentic ideas and thoughts, they were continuously unsure if the response fulfilled the expectations of the writing competition. This kind of imaginary connection created between the respondents and collectors has a strong impact on the final outcome and general status of the texts analysed. As I shall return to this question in the following chapters, I would like to draw attention to something else that appears significant in the discussion on cancer. Namely, in the instructions for the writing competition, the word *syöpä* (cancer, literally 'the eater') is used only twice if we exclude the names of cancer organisations and their publications. Rather, the instructions use the words "long-term" and "serious illness", or simply "illness". From my point of view it is difficult to decide if this was a conscious or subconscious decision by the organisers. However, the analysed cancer

narratives point to participants' anticipation of the word *syöpä* and problems with using it in their writing:

*Syöpä. Jo itse sanakin oli jotain niin kuvottavan inhottavaa kuin vain saatoin tietää. Suomeksi tuolle sairaudelle on keksitty todella hyvä nimi: jotain, joka tulee varkain ihmiseen ja kirjaimellisesti syö, hävittää ihmisen pois.*

The eater. Already the word itself was the most terrible and awful thing I knew. In Finnish they have given a really good name to that illness: something that secretly comes and enters the human and quite literally eats, destroys, the human being. (401)<sup>1</sup>

If the organisers' decision to avoid the word was subconscious, this would quite clearly show a culturally agreed fear of the word cancer.

## Becoming familiar with resources

The results of the writing competition were magnificent: altogether 672 cancer narratives - all in all 6 384 pages - were received filled with experiences relating to cancer. Compared to other writing competitions organised at the same time, only a competition called *Työttömän tarina*, discussing unemployment (1992), received more answers (Laaksonen & Piela 1993, 10). The importance of this particular topic is explained by the fact that the beginning of the 1990s was marked by economic depression in Finland, in which many people lost their jobs. In order to contextualise the collected data and to gain a clear insight, it is important to consider the political and economic circumstances of the time. After the industrial growth of the 1970s and 1980s, the beginning of 1990s was a period of economic crisis. The main reason behind this was the collapse of the Soviet Union, as 15–20% of Finnish export products were produced for the markets of their eastern neighbour, resulting in an economic crisis that was even worse than that after World War II. Unemployment rose to nearly 20% (Kiander & Vartia 1998) businesses went bankrupt and many people lost their incomes. This crisis influenced politics and culture, and caused depression and hopelessness across the whole nation. Having health problems in such

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<sup>1</sup> Here and elsewhere in this thesis I refer to the competition text examples only with archival number. The original texts as well as detailed information about the respondents may be gained from the Folklore Archive of the Finnish Literature Society. The extended archive references are also given at the end of this thesis.

social and economic circumstances added some difficulty to the personal illness experience and made it worth sharing.

In the following table I have listed the various writing competitions organised by the Folklore Archive at the Finnish Literary Society dealing with health and other medical issues (see Figure 1). The table indicates that in the history of writing competitions relating to health and medicine, only the ethnomedical questionnaire *Medica* (1964), and the personal experience stories about tuberculosis *Parantola* (1971), received more responses.

Name of the writing competition	Year(s) of collecting	Responses received
<i>Kansanlääkintään liittyviä kyselyjä</i> (Folk medicine questionnaire)	1950	608 units
<i>Lääkäri- ja muita kaskuja</i> (Jokes and tall tales about doctors)	1953	106 pages
<b><i>Medica</i> (Folk medicine)</b>	<b>1964</b>	<b>8 720 units, 957 respondents</b>
<b><i>Parantola</i> (Tuberculosis)</b>	<b>1971</b>	<b>9 000 pages, 350 respondents</b>
<i>Kansanlääkintä. Kansanparannuksen kilpakeräys</i> (Folk medicine)	1978	2 500 pages, 397 respondents
<i>Apteekki</i> (Pharmacy)	1980	256 pages, 44 respondents
<i>Kuukautiskysely</i> (Menstruation)	1982	511 pages, 98 respondents
<i>Reumaperinne</i> (Rheumatism)	1991	2 583 pages, 203 respondents
<b><i>Kun sairastuin syöpään</i> (When I fell ill with cancer)</b>	<b>1994</b>	<b>6 348 pages, 671 respondents</b>
<i>Hoitotyö</i> (Nursing)	1998	5 658 pages, 169 respondents
<i>Vanhemman kuolema</i> (Parents' death)	2001	87 respondents
<i>Hammashoito</i> (Dental care)	2001-2002	1 450 pages, 98 respondents
<i>Kansanlääkintä Pohjois-Karjalassa</i> (Folk medicine in northern Karelia)	2001-2002	114 respondents
<i>Lääkärintyö</i> (Doctors' work)	2004	1 300 pages, 60 respondents

Figure 1. Writing competitions dealing with folk medicine, popular health and medicine

In the cancer narratives, the impact of this period of depression is fresh in writers' minds. Presumably the period of economic and social crisis made society more open to the pressures and concerns of the individual. Because of cultural attitudes that are deeply tied with the fear of cancer in Finnish society, it is difficult to imagine that the writing competition would have been more successful earlier. The large number of respondents allows the suggestion that 1994 was exactly the right time to collect these cancer experiences, as members of this depressed society were ready to share their individual fears and suffering, making them more willing to talk about their cancer experiences as well.

As I worked through my resources, I had to make some corrections to previously given information concerning the participants' gender division. My minor corrections are mainly the results of observations made on the content of the cancer narratives. These observations increased the number of male participants from 67 to 73 and the number of female participants from the 594 to 599 (Hietanen & Nirkko 1996, 7). The difference is understandable, as the statistic posed by Nirkko and Hietanen is based on the personal data added to the cancer narratives. However, content analysis revealed that the sender, as given in the header of each narrative, sometimes only had the role of mediator, as the actual text was composed by someone else. Thus, the experiences described in the cancer narratives may actually belong to someone other than the name indicated in the archival reference. For example, if it was stated within a story that a sister had written down her brother's cancer experience and sent it to the archive (139), I listed the narrative as a male experience for further examination.

The gender division among participants means that the sample is dominated by female respondents (see Figure 2), which is characteristic to most of such archival calls. Altogether 89% of participants were female, a statistic that in itself gives certain information relevant to the discussion of cancer-related themes. In recent years studies have emphasised the medicalisation of females in various contexts within Western medicine (Helman 2000, 114–118). However, this does not explain why women have been more active in sharing their cancer experiences. Based on societal norms and agreements women have historically been more engaged with all kinds of medical systems, from preventative to complementary and alternative treatments. In addition, the fields of self-healing and domestic healthcare are typically dominated by women. Although men may share this knowledge, it is usually women who carry out the preventative and curative practices that take care of all family members. As women are more engaged with health problems in the domestic sphere and in other areas connected with health and popular healthcare, they generally gain more medical experience than men. Female dominance when it comes to sharing the individual cancer experience is also observable on the Internet forum for Finnish cancer patients, in which women are far more active and involved than men. As women seem more interested in their health than men, the dominance of female participants may also have something to do with the survival rates of cancer patients as, among the contributors, are numerous women who have survived breast or gynaecological carcinomas.



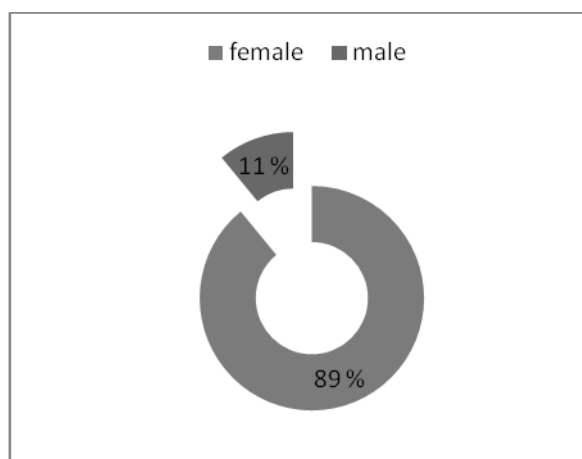


Figure 2. Gender division among writing competition participants

The slight increase in the number of respondents compared to Hietanen and Nirkko's suggestion is caused by fact that some of the narratives received were composed by two or more people sharing different perspectives on the same situation. Making a division between such inputs was complicated as the techniques for composing the cancer narratives are multiple, particularly as the situations differ radically. For example, an account written in memoriam of a cancer patient may include the cancer patient's diary references, letters, or other notes, combined with photos and personal reminiscences from the person composing the story (406). Although, such a story gives two different insights to a situation, it must be viewed as single archival account. On the other hand, if two people describe the same illness course from their personal points of view (086 and 087), both accounts may be analysed as two separate personal cancer narratives. Because, in addition to cancer patients, others, for example relatives and close friends, contributed their thoughts and experiences, it is somewhat complicated to evaluate the data from the personal experience point of view. What I mean here is that the autobiographical value diminishes in such narratives and is replaced instead with detailed ethnographical descriptions concerning the lived experience.

It is rather common for the collected cancer narratives to include references to different cancer patients and their experiences. For example, a woman from central Finland analysed altogether 14 different cases of cancer experienced by her colleagues and friends (394). This raises an important question concerning the actual cancer experience. Does the experience belong to the cancer patient, or may anyone familiar with cancer and capable of composing a narrative be interpreted as having a personal cancer experience? I suggest that, compared to other accounts among the cancer narratives, those of personal experience

are more profound because such stories concentrate on the important dialogue between the personal cancer experience and culturally accepted ideas, as well as social and societal practices. As the following figure shows, cancer patients' personal records (482 examples) form almost 75% of the available material (see Figure 3). For the sake of clarity I have excluded accounts that detail numerous other experiences in addition to the cancer experience, as in my opinion they contain significantly less value to this examination. In this work, however, I analyse the materials received from cancer patient's friends and relatives, as their secondary experiences include equally interesting data in the ethnographic sense. Furthermore, the descriptions of death and dying in the cancer narratives analysed in the final chapter come only from the perspective of secondary observers.

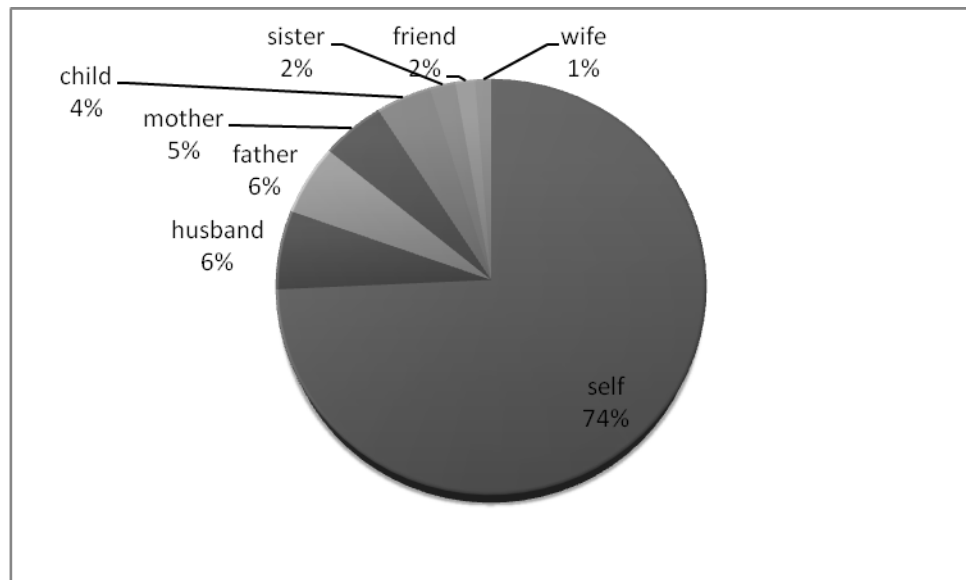


Figure 3. The main protagonist in the cancer narratives

The participants' profession was among the required information of the writing competition and quite obviously female dominance among the respondents affected the list of dominant professions. Accordingly, the most common occupations among the participants were teacher, office worker, and medical worker (physician, nurse, midwife). The cancer narratives also indicate that this same group of (lower middle-class) women is the largest sub-group within those who volunteer for various cancer patients' support projects, and this offers an additional reason for their great interest in this kind of writing competition. Among the male participants the profession-based distinction is more varied and without any clear peculiarity.

The age distinction among respondents was rather extensive as the youngest respondent was 12 and the oldest 98 years old. The most active writers were between 50–54 years and 70–74 years old. Among the writers were many retired people, who actively participate in all kinds of calls for writing. It is important to note that in the cancer narratives the patient’s age when falling ill has great significance. Often the cancer patients’ ages when falling ill are explicitly expressed in the cancer narratives. In cases where this data was missing I compared the required information and the information given in the texts (the year of falling ill). The following diagram (see Figure 4) represents my, to some extent rough, calculations of respondents’ ages when becoming ill with cancer.

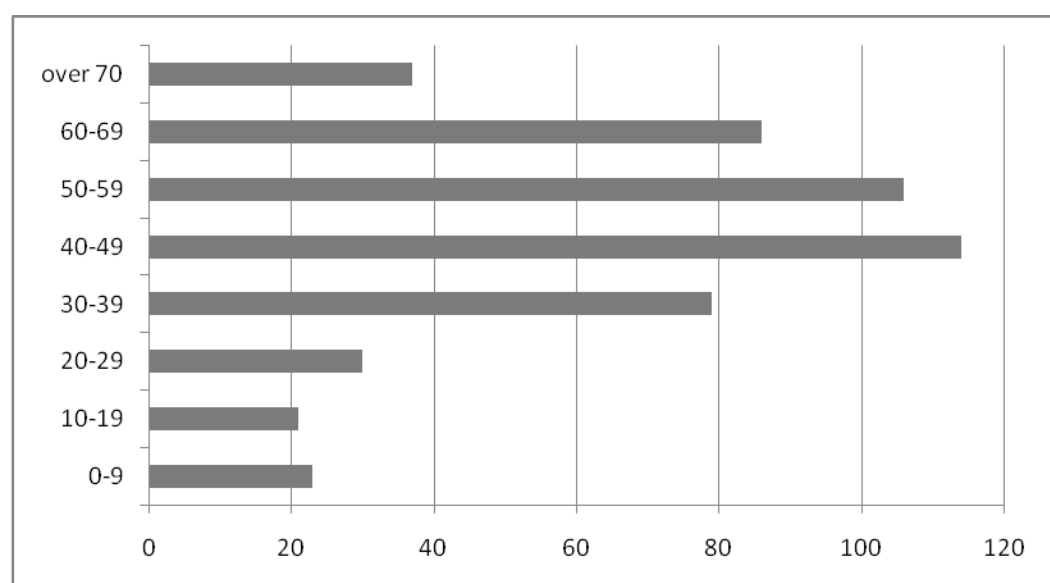


Figure 4. The age of falling ill

People have certain expectations regarding a ‘normal’ lifespan and therefore it is difficult to accept an illness that for some reason strikes “too early” (Finnish Cancer Registry, Statistics: incidence by age). Naturally, individual expectations of lifespan vary, although in the case of cancer it is understandable that the illness, with its killing image, is interpreted differently by patients of different ages. If a child, youth or young adult falls ill, it is seen as more unnatural compared to the diagnosis of cancer in someone more mature who has had a long and eventful life. In the cancer narratives analysed here people often question how cancer can attack children and young people. In this manner, a 15-year-old leukaemia patient wonders:

*Mä en oikeastaan tiennyt mitään ennen sairastumistani tästä kyseisestä sairaudesta. Oikeastaan mä luulin, että vain vahoilla ihmisillä on syöpä. En mun mieleen tullutkaan, että lapset vois sairastua siihen. Nykyään Suomessa sairastuu noin 150 lasta vuodessa syöpään.*

Actually I didn't know anything about this illness before falling ill. I actually believed that only old people have cancer. It didn't enter my mind that children could fall ill with it. Today in Finland about 150 children fall ill with cancer every year. (057)

The belief that cancer only threatens people in their old age is closely connected with medical history. In antiquity many observations were made regarding cancer, but for a long time cancer occurrences were connected with particular age and gender aspects of society. For example, in 1700 Italian physician Bernardino Ramazzini (1633–1714) noted that breast cancer is very common among nuns. Other cancer forms became diagnosable after studies with the microscopic, and pathology, developed. Finally, cell theory, developed by the German Rudolf Virchow (1821–1902), radically transformed the medical (micro-level) understanding of cancer (Porter 1999, 575). Typical to popular reasoning, such early ideas and discoveries affected health beliefs and so it is understandable that respondents emphasise the patients' age of illness.

Social studies have demonstrated that equality in health and healthcare has, generally speaking, been consistent despite political and economic problems in Finland (Kautto 2003, 3, Lahelma et al. 2001, 2–3). Although variation among different social groups is small, I would like to point out that general health behaviour in cities and villages, or small towns, has at least two significant differences that influence respondents' arguments concerning their illness experience. Furthermore, based on material at hand there also appear to be some meaningful dissimilarities between the healthcare offered in urban areas, and that offered in country areas.

The following map (see Figure 5) demonstrates roughly the places from where the writing competition entries originated. The map offers a general overview of the collected materials, and how these texts represent different parts of Finland. Unfortunately, the map does not mediate the accurate place of residence, the location where the cancer was discovered or where treatments were received. The map demonstrates that a large amount of material comes from urbanised areas of Finland. Helsinki city and the Uusimaa region are the most intensively populated areas of Finland, and therefore it is not surprising that 23% of all respondents come from this region. The other two rather well represented areas are the Turku/Pori (Varsinais-Suomi, Satakunta) region and Tampere city and its

surroundings (Häme, Pirkanmaa). Other areas of Finland are represented quite equally, except the eastern part (Mikkeli, Savonlinna, and Lappeenranta). Among the participants there were also four expatriate Finns, and four respondents did not add their address (although it was requested in the competition instructions). It is quite typical that the competition was more successful among people living in cities and small towns than among those living elsewhere.

Compared to similar writing competitions *Työttömän tarina* (1993) and *Maan sydämeltä* (1996–1997), organised by the Finnish Literary Society's Folklore Archive, the writing competition examined here shows few differences among the respondents' geographical origin. Perhaps the number of Swedish speaking Finns was higher than usual (*Käsitöiden aineistoluettelo*).

This leads to the hypothesis that the idea of discussing the cancer experience is somewhat more accepted in urban areas than in the countryside, although the idea of hiding cancer from others seems typical to cancer discourse in general. The principal change across time has been medical and public attitudes towards the discussion of cancer. People fear their illness and its outcome, but additionally they fear other people's reactions and behaviour as they hear about a diagnosis of cancer. Roy Porter, the author of the outstanding medical history *The Greatest Benefit to Mankind* (1997), has described cancer "as the modern disease par excellence that became the subject of terrible taboos, seen not just as fatal but as psychogenic, the product of a so-called 'cancer personality', the self that eats itself away through frustration and repressed anger" (Porter 1999, 574). Such personality bound myth has helped shape the secretive nature of cancer and made the disease in many societies unmentionable.

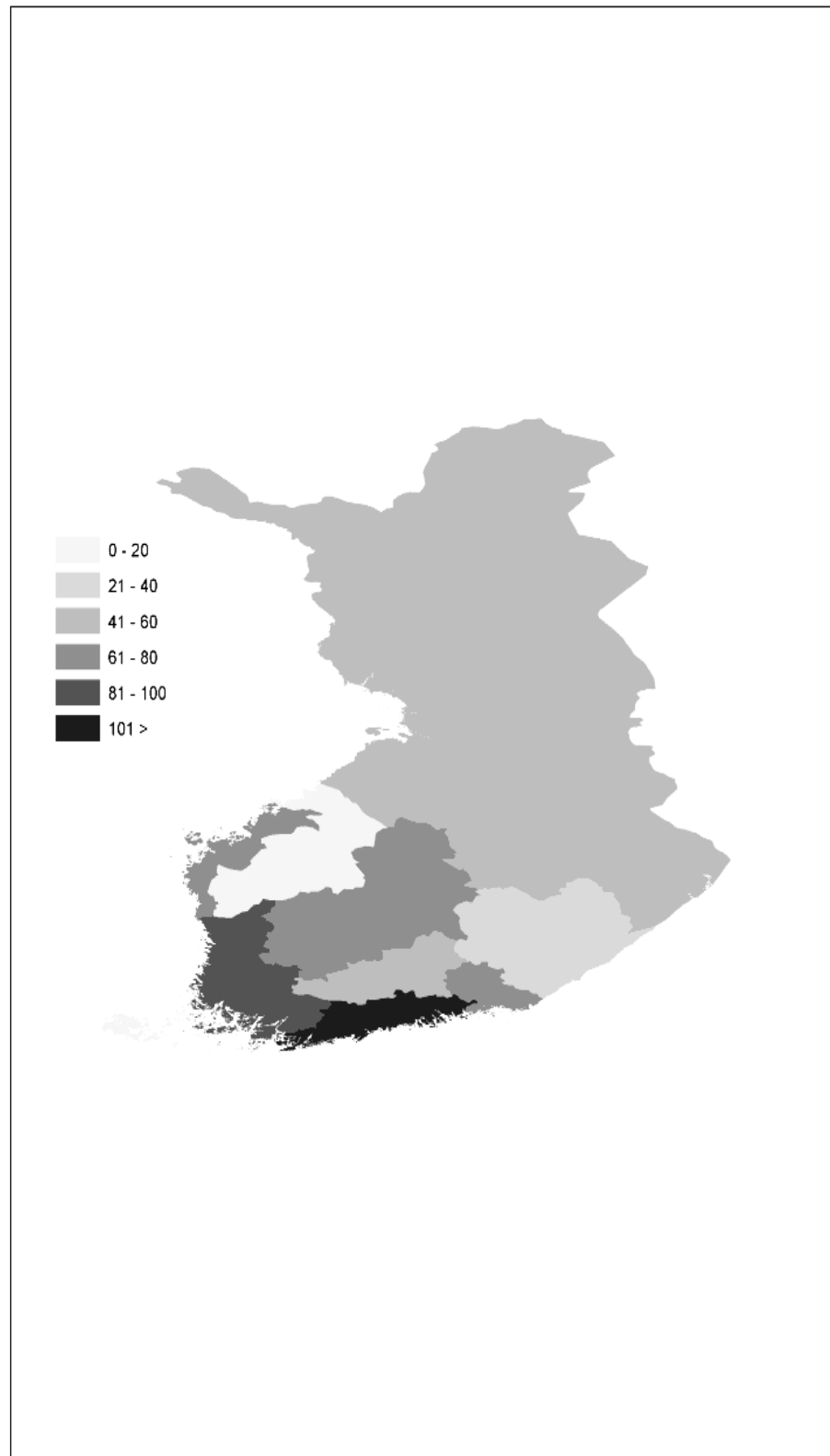


Figure 5. The participants' places of residence

The cancer narratives indicate that several aspects of cancer patient behaviour are dependent on a patient's place of residence (see Finnish Cancer Registry, Statistics: incidence by central hospital district). As I pointed out above, the dividing line is generally between country and urban communities. According to the materials analysed, a patient's geographical location within Finland affects his or her access to medical services and also their general attitude towards doctors and illness. In the cities people are forced to go from one doctor to another, getting lost in a tunnel of expertise. For example, one respondent described visiting 26 (125) and the other 43 (257) different medical professionals during the two years after being diagnosed with cancer. In the countryside, on the other hand, people may undergo feelings of embarrassment and frustration, as the single available doctor is incapable or unwilling to diagnose the reasons for patients' tiredness and lack of energy as the early symptoms of cancer because of professional supremacy (048, 061). In both cases it is notable that people are unsatisfied with the way medical healthcare is organised and made accessible to ordinary people.

The other significant difference between urban and country communities is connected with the culturally stigmatising image of cancer. It appears that in the countryside people evaluate and reflect their experiences more through collective experience and are more influenced by the opinions and judgements of neighbours: "*Sehän on sensaatio meidän pienessä kylässä, kun sairastuin rintasyöpään*". "It is a sensation in our little village, that I fell ill with breast cancer." (398) Being surrounded by a local community may be experienced as supportive; however, in many cases it causes feelings of being misjudged and abandoned.

The cities dominate individual attitudes and norms of behaviour. In the urban context people may, at least to some extent, hide their illness from relatives, friends and work colleagues, or select with whom they share their illness experience (087, 465). This, however, makes them suffer from loneliness and a lack of support: "*Olen koko ikäni pelännyt tunteiden voimaa ja järkeistänyt kaiken. Olen liian hyvin sisäistänyt meidän itsehillintää ihannoivan kulttuurimme, jossa heikkoutta ja surua ei sovi näyttää*". "I have, all my life, been afraid of the power of feelings and kept everything reasonable. I have accepted our culture of admiring self-control, in which it is not proper to see weaknesses too well." (412) Moving towards analysing the everyday problems of cancer patients, I emphasise that social misjudgements towards cancer patients are one of the greatest challenges to all cancer patients, and therefore discussing this issue is highly important. In order to do so, I shall take this issue up later (see Chapter 5).

To describe the resources used in this thesis properly it is also important to define the dates of the events described in the cancer narratives. Although the writing competition was organised in 1994, the texts focus on various personal experiences representing different decades of the 20<sup>th</sup> century. A few of the personal experiences lead back to events that took place at the beginning of that century (001, 047, 197). The majority of the cancer narratives concentrate on events occurring during the second half of the 20<sup>th</sup> century, starting from the 1950s. Figure 6 indicates that the largest amount of material concentrates on experiences gained in the 1980s and the beginning of the 1990s.

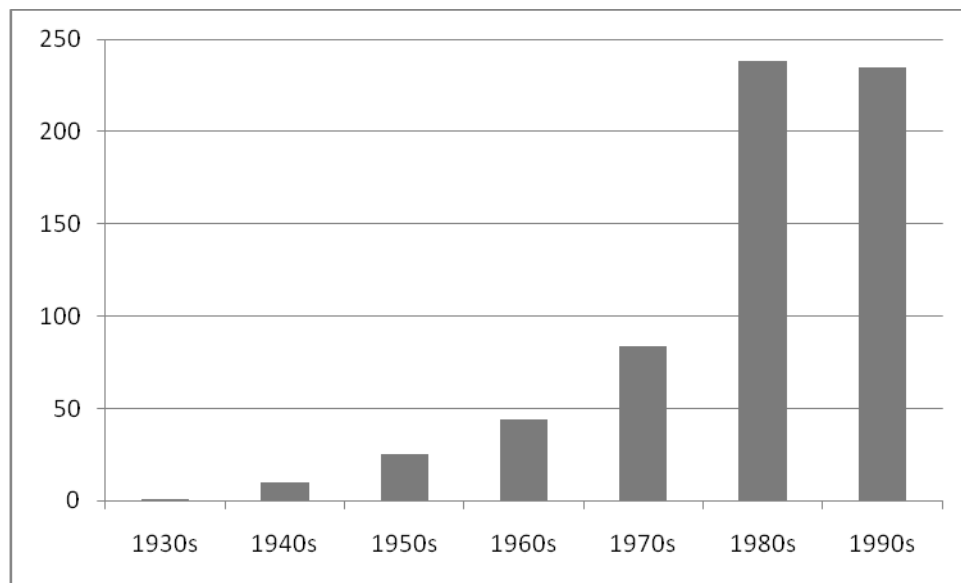


Figure 6. The dates of events described in the cancer narratives

This expanded timescale also influences the way that cancer narratives are written. The positive aspect to this is that the extended timescale allows observation of the developments in cultural attitudes towards cancer. Cancer patients who experienced cancer some time ago make useful remarks and observations in their writing on the differences between having cancer “then” and “now” (for example 590, 600, 608, 620, etc.) and their own experiences are often compared with those of their parents or relatives (586, 596, 601, 611).

For a long time cancer patients treated in healthcare centres were not aware of the name of their disease, and quite often the reason for their deaths was hidden from their relatives. As the following example demonstrates, the changes in attitudes towards discussing cancer with patients, and also in public, came in the 1980s and 1990s, and is still in progress today:



*Ei siihen aikaan puhuttu paljon syövästä, tokkopa aina tiedettiin kukaan kuolinsyytä. [1977] Tänä päivänä syövästä puhutaan, siitä tiedetään sitä tutkitaan, pyritään pääsemään mahdollisimman pienillä vauriolla, menetyksillä. Mammografia lienee tärkein anti naisille yhteiskunnan taholta. Toivoisi joukkotutkimusten lisääntyvän myös nuoremmille naisille. Vuonna 1986 ei syövästä paljon puhuttu, ei käytetty paljoakaan mammografiaa. Tuntui, että se oli suorastaan kielletty paha puheenaihe.*

At that time [1977] people did not talk much about cancer, one hardly knew the reason of death. Today people discuss cancer, they study it, and try to cause as little harm and as few losses as possible. Mammography appears to be the best thing offered to women on behalf of society. I hope there will also be more screenings for younger women. In 1986 people did not talk about cancer much, they did not use mammography either. It seemed that it was almost a forbidden, 'bad', topic. (185)

The issue of dates in the cancer narratives is complex because the 20<sup>th</sup> century has been full of social reforms. Changes have taken place in all areas. The development of the Finnish healthcare system has been very rapid considering that at the beginning of the 20<sup>th</sup> century most Finns still used different folk medical practises to treat even serious health concerns, which they did at home. At that time the few available county doctors had to manage with limited resources, which meant that the local healer's skills were far more available to ordinary people than the expertise of a trained doctor (Naakka-Korhonen 1997, 108). Later, during the Second World War, governmental efforts centred on the daily survival of the nation. Thus, the active period of social reforms and the process of reorganising the healthcare system, linked with the building of centralised hospitals, began in the 1960s. Since then most serious illnesses have been taken care of in the hospitals and healthcare centres using the methods of evidence-based medicine or biomedicine.

The available biomedical cancer treatments have developed hand in hand with changes in the healthcare system. The treatments have been influenced by discoveries and developments concerning cancer. The dominant role of biomedicine in state supported healthcare centres has led to a situation in which the majority of Finns trust, and only use, the officially approved biomedical cures. The unfortunate truth in this situation is that despite the amount of money and the efforts of different research groups, the human understanding of cancer is still limited, and therefore the various treatments offered to cancer patients offer relief accompanied by serious side-effects, rather than a cure (Porter 1999, 577). Therefore, the crucial question is how much the change in the healthcare

system and the advances in available treatments have actually shaped people's attitudes towards cancer. Through an historical insight into Finnish folk medicine, and the available cancer narratives, I shall return to this subject in this study where it touches upon various situations.

Official statistics about instances of cancer in Finland are available from 1953. Since then, medical institutions and practising physicians have been asked to inform *Suomen Syöpärekisteri* (the Finnish Cancer Registry) of all diagnosed and suspected cases of cancer. Since 1961 this has been compulsory (Finnish Cancer Registry). Markku Koskenvuo, professor of public health at the University of Helsinki, has listed the ten most common cancer types in Finland. Per 100 000 people the cancer death rates for men and women were as follows: lung cancer (89/13), gastric/stomach cancer (25/13), pancreatic cancer (19/15), breast cancer (0/27), colon cancer (15/13), prostate cancer (43/0), blood cancers (15/9), rectal cancer (12/7), lymphoid tissue cancers (11/7) and ovarian cancer (0/12). In his epidemiological insight *Kansantaudit – esiintyminen, riskitekijät ja tutkimusmenetelmät* (National diseases – statistics, risks and research methodologies) Koskenvuo proposes that the most common cancer types form 70% of all cancers, while during the years between 1971 and 1991 deaths caused by cancers have diminished by almost 20% (Koskenvuo 1994, 43). Despite the improvements in cancer prevention, such as state supported screenings for certain age groups, etc., cancer is still a serious problem affecting human lives.

The available statistics give a good opportunity to evaluate the representativeness of the collected materials in terms of the most common cancer types, although according to my expertise in popular reasoning, the particular cancer type is of secondary significance. As I shall point out later in this thesis, unlike biomedicine the irrational concept of cancer typical to popular reasoning interprets every cancer as unique, while at the same time, and quite to the contrary, generalising all cancer types under one heading — 'the eater'. However, I also presume that as this particular writing competition was organised in cooperation with cancer associations, the respondents tried to be accurate in giving medical details: "*Toivon kuitenkin, että tämä luku on oikein, koska pyrin siihen, että tämä kertomukseni olisi lääketieteellisesti mahdollisimman luotettava!*" "I hope this part is correct as I try to make my narrative medically as reliable as possible!" (060)

The participants' attempts to be correct when sharing medical information (including the type of cancer) is connected with their primary idea, or even hope, that oncologists and other medical practitioners would examine their writing at some point.

In Figure 7, representing the qualities of available resources (see the List of Extended Archive References), only the cancer types that appeared more than twenty times in the text corpus are presented. More than ten texts were about prostate, pancreatic, kidney, thyroid and brain cancer, while there were less than ten texts about liver or bladder cancer in the corpus. In creating this diagram, I avoided using exact numbers as many of the stories do not explicitly mention what type of cancer was concerned. In several cases the patients also suffered from a recurrence of a previous cancer, which also means possible metastasis in different body parts. This explains why the category for various and unmentioned cancer types is so large.

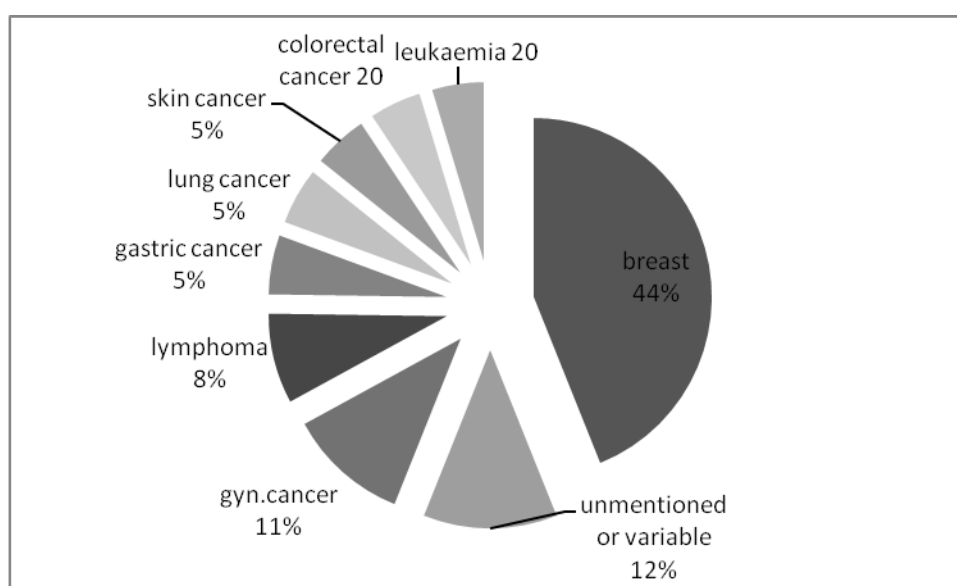


Figure 7. The most common cancer types in the cancer narratives

The large number of records about breast and gynaecological cancer is well understandable when considering that female participants were more active than male. On the other hand, the large number of female cancer experiences is explainable by the fact that since the 1970s, breast cancer particularly has been widely discussed in various mass media channels. I emphasise that this kind of open discussion has worked as an encouragement for the participants, and that open discussions have led to more competent controls, and accordingly an increase in the survival rates among female cancer patients.

The number of male participants in the writing competition was small. There were only ten records from sufferers of prostate cancer, even though prostate cancer has become the most common cancer among Finnish men in recent years (Matikainen 2001, 9). According to the Finnish Cancer registry, 1 586 new cases of prostate cancer were registered during

the years 1989 to 1993. The number of new breast cancer cases among Finnish women was 2 664 in the same period. Since I have followed cancer discussions intensively in the mass media, I am convinced that today men share their experiences concerning prostate cancer with less hesitation than they did in 1994, and it would seem that this is a very positive trend, one that highlights the importance of open discussion in coping with any disease.

All in all, the cancer narratives analysed for this thesis do form a representative corpus: there is a total of 6 384 pages filled with personal cancer experiences. The main advantage of resources like those used in this thesis, collected via the writing competition, is that participants may share their lived experience from the personal perspective without fear of being evaluated as cancer patients. Of course, the participants of a writing competition are aware that their texts will be read and judged as writing, and they are influenced by the questions posed. However, during the writing process they are not affected by the influence of communication, as they are in daily discussions. This means that in thematic writing respondents may express themselves more openly, selecting more suitable and accurate words and expressions than in, for example, interview situations where the emphasis on communicative aspects is much higher. Performance-based narrative studies have shown that when being interviewed, people make strategic decisions and adapt their experiences, taking into account the performance context and the receiver's (interviewer's) expectations (Siikala 1990, 27–35). The benefit of written cancer narratives is that they have developed from the individual negotiation process. Because they are delivered in a written manner they represent a 'truer' version of events: the feelings, thoughts and experiences of participants offer multiple possibilities for textual interpretation.

## **Sources providing context: letters, ethnomedical records and Internet forums**

The reliability of sources may be increased by expanding the understanding of context. Therefore, I have selected some additional sources to augment the results of the writing competition. The letters are added to the original writing submitted to the competition and work as co-texts or metanarratives; they are particularly useful in understanding and interpreting the primary aims of the participants. The ethnomedical records, on the other hand, offer a diachronic insight into popular ideas relating to cancer before the modern healthcare system gained its dominant position in Finland. Additionally, the few cancer

narratives collected from Estonia, and cancer patients' internet discussions, form a good grounding for comparative studies.

Respondents' letters, including personal data, remarks about the writing process and its meaning for the writer, form a very useful guide to context when analysing participants' perspectives as well as the writing process. In these co-texts, people explain and analyse the composed cancer narratives, representing individual attitudes and challenges of writing down personal experience in the following manner:

*Oheisena on kirjoitukseni mieheni sairastumisesta syöpään ja hänen kuolemastaan ja niistä ajatuksista ja tuntemuksista, joita niinä vuosina mielessäni ja muiden läheisten mielissä liikkui. Jo viime syksynä mieheni elokuussa tapahtuneen kuoleman jälkeisessä mieleni kaaoksessa aloin kirjoittaa tuntojani selkeyttääkseni ajatuksiani. Se osoittautuikin hyväksi keinoksi, kun aloin koota palasiksi menneen elämäni paloja yhteen. Kirjoittaminen selvitti ajatuksiani, aloin osata elää yksinkin jatkaen sellaista, mitä olimme tehneet yhdessä ja alkaen jotain aivan uutta juuri alkaneessa elämäni vaiheessa. Tämän tietäen poikani toi minulle ilmoituksen tästä kirjoituskilpailusta. Mielelläni tartuin tilaisuuteen, tosin en niin kauhean mielelläni kilpaile, mutta ehkä minun kokemuksestani on jollekulle jotain hyötyä tähän niin kauhean ja niin yleistyvään sairauteen liittyen.*

I send you my writing about my husband's cancer and death, and about the thoughts and feelings that were in my head and in the heads of my close ones during these years. I began to write down my thoughts already last year in August when my husband died. I wrote down my feelings in order to clear my thoughts. It appeared to be a good method as I began to gather the pieces of his past life. Writing cleared my mind and I learned to live alone, continuing to do things that we had done together. I began even to hope for something completely new. Knowing this, my son brought me a notice about this writing competition. I accepted this gladly. Thus, I would not like to take part in the competition, but maybe my experience will be useful for someone concerning this terrible, and today so common, illness. (354)

*Mutta mutta. Kuten kaikki "kirjailijat" (anteeksi nimitys), minäkin aion kertoa ratkaisun sekä sen, miten siihen päästiin, vasta aivan kirjoitukseni loppupuolella, jotta jännitys (onkohan sellaista?) ei lopahtaisi liian aikaisin. /---/ Nämä kysymykset ovat aivan ilmeisesti tarkoitettut ohjailemaan kilpailun osanottajia vastauksien laadinnassa. Tämä voi olla hyödyksikin, mutta minä en kuitenkaan voi muuta kuin kirjoittaa omalla tyylilläni.*

Well well. Like all ‘writers’ (forgive the name), I also aim to talk about the solution and how it was achieved in the final part of my writing, so that the excitement (if there is any?) would not stop too soon. [---] These questions are quite obviously meant to direct writing competition participants when composing their answers. This might be useful, but I can’t help writing in my own style. (060)

The first example argues about the meaning of writing in order to express and clarify one’s thoughts and feelings. The respondent also admires the idea of writing, although, she is not so excited about the idea of taking part in the competition. Like many other participants, she hopes that her writing might be useful and supportive for someone facing similar problems. The second co-text is quite interesting as it mediates the respondent’s attitudes towards her own writing skills. In the letter she is quite ironic about her own attempts to compose an engaging plot, while also comparing herself with writers. She also points out that she could not follow the open-ended questions posed by the organisers, but instead wrote the story in her own style.

The co-letters also inform us of the participant’s type as a respondent. In her book *Viinan voima* (The Power of Vodka), Satu Apo analysed the different types of respondent who participated in the sending of different folklore texts to the archive. Concerning these types, Apo has coined the term *kirjoittava kertoja* (the writing narrator). The writing narrator refers to a respondent who recalls and writes about his or her past; whereas a second type, *realistinen kaunokirjailija* (the realistic literate), refers to a person who makes an effort to give his or her text a literary value (Apo 2001, 17–18). I agree with Satu Apo in that, despite narrator types, the main value of such texts lays in their ethnographic significance. In the current case, the descriptions are of events connected to the processes of having cancer and ideas dealing with the subject. The extent of literary value does not change the quality of the text where that text is a fictive narrative. Because of the value of the writing, participants’ letters form an excellent source with which to analyse and interpret the primary aims of the participants as they composed their personal experience narratives. Doing so plays an important role in answering criticism concerning the interpretation of the texts, which I shall discuss below.

Ethnomedical archive records form a good source with which to survey the position of cancer before and during the period of modernisation (see Chapter 3). These accounts help us to understand the changes and improvements relating to both the concept of cancer and the available treatments. I have utilised the ethnomedical records (*kansanlääkintäkortisto*)

preserved in the Folklore Archive at the Finnish Literary Society to widen my understanding of the popular history of cancer. The ethnomedical materials were mainly collected during the second half of the 19<sup>th</sup> century and first half of the 20<sup>th</sup> century. Most of the gathered texts are based on a questionnaire called *Taikanuotta eli opas taikojen kerääjille* (Magic Net: A Guide for the Collector of Magic). This questionnaire was first devised by the archive in 1885 and later edited several times (Naakka-Korhonen 1997, 80–81). In the collecting instructions people were encouraged to describe various health problems, among them cancer, from the following perspectives:

- *How was the disease created?*
- *What kind of instruments, tricks and methods were used?*
- *How could a person become ill?*
- *What is the nature of this particular disease and how does it torture the ill person or animal?*
- *What kind of intermediate instruments or magic tricks were used in order to cure the disease?*
- *Why was this particular disease treated with these methods?* (Mustonen 1911, 38)

The collectors and informants were persuaded to give wider explanations about the reasons, symptoms, curative practices, and beliefs relating to various illnesses and diseases. Despite the questionnaire the ethnomedical records from the last decades of the 19<sup>th</sup> century and the beginning of the 20<sup>th</sup> century concentrate mainly on various folk medical treatments. In contrast to the cancer narratives, these texts rarely include personal experience accounts. Unlike other health problems recognised in an ethnomedical context, cancer has not created personal experience narratives, memorates or belief legends. Typically, informants describe the illness' origin and appropriate treatments very briefly, mainly because a lack of context makes the proper interpretation very complicated. Despite this lack of context, I found ethnomedical records an extremely useful source from which to gain historical insight into cancer discourse. Preserved ethnomedical texts form a unique source for the discussion and analysis of the curative practises used by cancer patients, as well as providing a way of analysing popular reasoning about the significance of cancer.

In 2005–2006 I made an attempt to organise a similar writing competition in Estonia, which, despite my efforts, resulted in only five responses. The material collected was extremely small, which made me consider the social circumstances in Finland in 1994 and

compare them with the situation in Estonia in 2005 and 2006. The year 1994 came after a period of harsh economic crisis that affected everyone in Finland. A period, which I suggest made people more sympathetic towards individual sorrows. In Estonia the years 2005 and 2006 were times of several economic and social reforms that affected people's welfare positively. This kind of radical period presumably left no place for the weak and diseased (for more, see *Minu vähihaigus*, <http://www.folklore.ee/era/kysitus/>).

While doing this research I have actively followed – and a few times under various names also participated in – the discussions on two Internet forums for Finnish (see Figure 8 *Syöpäjärjestöt*, [www.cancer.fi/keskustelut](http://www.cancer.fi/keskustelut)) and for Estonian (see Figure 9 *Vähiforum*, [www.kaev.ee](http://www.kaev.ee)) cancer patients. One of my main interests here was finding out if, perhaps, the problems discussed in 1994 became less acute. In this sense, the Internet discussions have certainly verified that having cancer still causes identical human problems to those expressed in cancer narrative more than a decade ago.

The Internet forums were created in order to give cancer patients an opportunity to share individual thoughts with other cancer patients. The cancer narratives obtained through the writing competitions and the debates held in Internet forums are rather different from each other. Despite the fact that, in the cancer narratives, people tackle similar themes to the cancer forum participants, the latter is based on pressing questions and problems and offers active communication, and usually also immediate feedback. Cancer narratives are written in the hope of sharing individual experience and provide the opportunity for self-analysis in the critical situation caused by illness.



Figure 8. [www.cancer.fi/keskustelut](http://www.cancer.fi/keskustelut) [05.11.2008]





Figure 9. www.kaev.ee [05.11.2008]

The reason I participated personally in Internet discussions was because of the pressing need to answer some research questions deriving from the materials analysed (see Chapter 5). I chose to participate in the discussions themselves only if I could not find a satisfactory answers from the forum or forum archive. When creating themes for discussion, my main aim was to search for some verification or extend the understanding of an ongoing problem. I must admit that the questions I posed did not cause active discussion. Typically I got few answers and it was not uncommon that the administrator of the forum was the only one who reacted to my problems or concerns. This work in the forums also confirmed that women are more open to discuss their problems than men, which ties in strongly with the gender division found in the writing competition participants. Despite the above, only partial, success, using the Internet as a source through which to extend my understanding of the materials at hand was an interesting experience and definitely worth doing in order to experience and understand how such discussions function. Above all I have used these Internet forums for comparison and verification of my ideas and thoughts about the main concerns that cancer patients have (see Chapter 5), and also to cover culture-bound ideas that arise when discussing cancer patients' illness experiences and other concerns.

## Approaching reliable results

Written cancer narrative form a body of empirical data that is suitable for content or textual analysis. Traditionally content analysis is a research method that uses a set of procedures to make valid inferences from texts, with the main goal being the derivation of certain categories based on the available data (Weber 2004, 117). Content analysis, combined with other scientific approaches, is a widely explored method of interpretation in folkloristic research (Apo 1990, 62). However, other fields of research concerning human behaviour and reasoning have also employed such combined methods. In this vein, the Finnish scholar Veikko Pietilä has suggested that most fruitful content analyses use a collection of methods in order to assemble information from the research materials and to construct ideas (Pietilä 1976, 53–54, see also Uotinen 2008, 133–135). This means that, although content analysis makes selection through consideration of themes, paragraphs, sentences, words or expressions that appear frequently when examining the source materials, if required some aspects of content are explained in wider context. I agree with Apo and Pietilä's suggestions that although, historically, content analysis has been classified into qualitative and quantitative textual analysis, for successful and accurate results it is useful to adopt both methods, as it allows a more comprehensive description of the source materials. Thus, in the current study I shall adopt content analysis in order to become familiar with the texts created by cancer patients and to pre-select the themes for further examination.

Approaching reliable results while manually selecting the subjects for further research is a complicated task. The tradition-bound demand for reality and truth of research results is a particularly delicate matter. In my view narrative-based analysis should aim to be truthful and fulfil certain scientific criteria, although the request for reality or truth, whatever the accurate definition of these terms may be, stays unachievable because 'the truth', as much as it is graspable, lies beyond any written data – it is 'written' only in people's minds.

The written texts preserved in archives are no longer directly connected to the events that took place in reality. As narrative representations, the preserved texts are in any case removed from 'true life' to a certain extent. The analysed cancer narratives represent the participants' interpretations of lived experiences. This interpretation means that participants' writing does not mediate the events that took place in life, but are a result of inner analysis, argument and selection in order to make the desired point. This means that, as the researcher, I am at least twice removed from the true events: the person who

originally wrote down the information is once removed from the source, and the researcher is removed from the writer by another degree (Rosnow & Rosenthal 2005, 92). This is an important notion in terms of the request for reality or truth within any narrative-based research. Despite this, I trust that the careful examination and sufficient contextualisation of the available resources allows an understanding of the narrative representation from an objective background.

First of all, to add to the extent of objectivity the source materials must be carefully examined before making the selection for further research. It is necessary to become very familiar with the existing material, as ideas for studies often emerge from interaction between a researcher's substantive interests and his or her intimate knowledge of the information contained in the available sources (Kiecolt & Nathan 2004, 134). This is significant when clarifying several questions concerning the data: How is the data collected? What are the primary aims of the collectors? Who are the respondents? How are the texts produced? What kind of sociocultural backgrounds do the respondents have? What is the central message of the texts? I attempt to find answers to these questions, which relate to the information on respondents and the conditions that affected the creation of their cancer narratives. In the following paragraphs I shall describe and analyse my own decision-making process as it relates to the selection of the materials for further research.

The original idea of organising the 1994 writing competition came from Päivi Hietanen, a Finnish oncologist working daily with cancer patients. I asked her about her aims for collecting cancer patients' experiences, and she said that she wanted some first-hand information that would help her to do her daily work. Similarly, in the text edition she has stated that a book version was published in order to help and support people with similar problems, as well as to inform medical workers about cancer patients' experiences (Hietanen & Nirkko 1996, 7). When I studied the cancer narratives for the first time in the folklore archive, I had an excellent opportunity to question the second person closely connected with the original writing competition, archive researcher Juha Nirkko, who kindly explained to me the writing competition's primary ideas, the evaluation process, and mediated the feelings that the received texts evoked as they were gathered. This however did not stop me from creating my own ideas about the issues that these cancer narratives present. My background as a folklorist, and previous research interests relating to folk legends and folk medicine, made me focus on the character of the composed narratives and popular discourse on cancer as an illness.

In a way the whole text-based interpretation process is dependent on a researcher's position. Laura Stark-Arola has written that intuition and prior knowledge play an important role in constructing hypotheses, and that the problem of intersubjectivity (how one's own presence and subjectivity influences analysis and interpretation) means that the researcher is less a discoverer or even interpreter of meaning than a maker of it, and that the role of his or her own culture-bound thought process must be acknowledged (Stark-Arola 1998, 67; see also Apo 2001, 37; Apo 1990, 77). Although the primary aim in the current study is to gain information about cancer patients' thoughts, experiences and feelings, one must agree that it is somewhat impossible to avoid intersubjective impressions; that is, the thoughts, feelings and experiences that the available resources create in me.

Source materials or texts are highly respected among folklorists, and therefore the materials and central question(s) concerning the interpretation of cultural phenomena often alter the research method(s) used. The concept 'text' is used as a metaphor for all sign systems of human making, and these systems contain meaning which can be "discovered", "read", or "decoded" (Stark-Arola 1998, 67). Thus, the preliminary assumption is that the events, thoughts and feelings described in cancer narratives offer an insight into the complex network of individual reasoning and socioculturally accepted norms and ideas relating to cancer. Dealing with texts means the researcher must aim to understand, or 'decode', the meaning of the available sources. Interpretation of written texts means that researchers give meaning and significance to words that are not originally theirs. In his book *Validity in Interpretation* Eric Hirsch Jr. has claimed somewhat radically that, "since the meaning (parole) represented by a text is that of another, the interpreter can never be certain that his reading is correct" (Hirsch 1967, 235). Hirsch proposes that the researcher knows that the norms of language by themselves are far too broad to specify the particular meanings and emphases represented by the text. With this statement Hirsch argues that peculiar meanings specified by particular kinds of subjective acts on the part of the author remain in any case inaccessible.

I agree with Hirsch's assumption to a certain extent. As a folklorist interested in the processes of narrative self-expression, I am aware of various aspects that might influence oral communication as a written self-expression process. Compared to oral performance, the writing process is a subjective act of self-expression, filled with the writer's peculiar meanings. Furthermore it contains numerous rules and limitations set by cancer discourse as well as by the process of creating a written text. It is natural that as cancer narratives are

constructed on the bases of individual experience of the illness process, the events presented therein carry variable individual (primary) meanings and intentions. Somewhat characteristic to thematic writing is the fact that some parts of the received materials are written in order to describe, others to argue, and yet others to relate important thoughts or significant emotions. Nevertheless, the dominant intention among the writers appears to be the desire to communicate, describe the lived experience, and finally, make a point:

*Minun tarinani on tavallisen rintasyövän tarina, mikäli nyt ylipäättään syöpään sairastumista voidaan tavalliseksi sanoa. Siinä ei ole järjestyttävää dramatiikkaa, kuten esimerkiksi huonoennusteisessa leukemiassa tai tapauksessa, jossa pienten lasten äidiltä löydetään yllättäen laajalle levinnyt nopeasti kuolemaan johtava syöpä. Mutta minkä sielun myrskyn tavallinenkin tapaus synnyttää! Kaikki muuttuu hetkessä, sillä sanalla syöpä on kuoleman kaiku. Mutta se on myöskin haaste, kutsu taisteluun elämän puolesta periksi antamatta.*

My story is an ordinary breast cancer story, if falling ill with cancer may be called ordinary. There is now appalling drama, like in the cases where the mother of small children is diagnosed with leukaemia or other widely spread carcinoma. However, the ordinary case may also cause a storm! Everything changes in a moment, as the word cancer echoes like death. But this is also a challenge, a challenge to fight for life without giving up. (428)

The cancer narrative is created with the aim of communicating something significant. Thus, the researcher's primary aim becomes understanding the meaning of a given text. Accordingly, the first time the researcher receives the spontaneous meanings is when reading and observing the texts. At this level the meanings of the received information are given by individual intuition, rules of understanding and sociocultural context (Siikala & Siikala 2005, 132–139). Observation then shifts from the intuitive level to the research level, which is affected by the existing text corpus, primary and secondary research questions and the methodological approach. As argued before, spontaneous meanings and individual cultural expectations add a certain amount of intersubjectivity to any work based on texts. This means that scholars interpret the sources according to their own experiences and sociocultural understanding, and so a respondent's meanings as expressed in text becomes newly interpreted and placed in an entirely different context, as defined by the selected research paradigm.

While reading and studying the materials at hand it was apparent that the writers' intentions were unclear and I felt the required tools for understanding were, somewhat, lost or hidden. This, however, did not make the whole thematic account meaningless, particularly within the framework of the thick text corpus. Despite numerous problems that limited accessibility to the writers' primary intentions, I suggest that studies based on a large text corpus offer an excellent opportunity to examine and reliably interpret the sociocultural images of any theme with particular significance. In this vein, the French philosopher Paul Ricoeur has emphasised that instead of being unclear, people want to be understood. Thus, writers use various methods in order to formulate their thoughts and express themselves in a comprehensible manner (Ricoeur 1974, 104–107). The words or expressions used by participants, as well as the primary meanings of the composed narratives, cannot have infinite ambiguity as otherwise the communication would fail (Lindqvist 1981, 25).

I emphasise that the texts under study may be approached as accounts intended to inform the reader. In this way the central ideas that are conveyed via thematic writing as a whole, in comparison to other kinds of narrative, take priority over the writer's primary intention, which is captured in the descriptive or narrative parts that are used to compose the thematic narrative. For both the reader and the researcher, thematic writing offers an opportunity to follow particular culture-bound discourses containing respondents' central concerns as well as the impact of their experiences.

Satu Apo has proposed that written narratives create an intertextual universe within certain contextual frames (Apo 1995, 139). I advocate that within these frames the participants are interested in sharing their knowledge and experience, which at first means respecting their 'voicings'. Voicings that may be concrete or metaphoric, but which lead to the researcher's interpretations within the selected methodological frames (Fingerroos & Kurki 2008, 14–15). As a researcher, I am interested in studying the ethnographic information captured in cancer narratives, and even more in finding answers to the questions posed within the available methodological frameworks. Thus, my interpretation of the written texts does not denote finding the writers' primary intentions, rather that the foremost interpretation is a challenging multi-levelled task of building up a reliable contextual frameworks for the study of the multiple, culture-bound, meanings within cancer discourse.

## Selecting materials for further discussion

A researcher must analyse the content of his or her chosen texts to decide on the analytical units to be used, and this necessitates the selection of topics for further discussion. As I argued above, the selection process is mainly dependent on a researcher's choices and the research question(s) posed. In a way, the researcher creates a certain model that presents the research materials in a more limited and generalised mode (Pietilä 1976, 93; Wersig 1968, 14–15). In the textual analysis, the analytical unit may be the whole narrative, but may also be limited to significant words or expressions. Later the selected analytical units will be interpreted according to research question(s) and research method(s) presented at the beginning of each chapter.

Making the selection is partly an intuitive process (Apo 1995, 37) and therefore challenging to describe here. To start with, I examined the materials connected to organising the writing competition. After this I began to read and make notes about the available sources in order to extend my understanding of the information given in the materials. While reading and examining the texts I created a database that helped me to situate the available data. To extend my knowledge of the materials and participants I wrote down, as accurately as possible, the following information:

1. Archive number of the source (from 1 to 671)
2. Page numbers in archive (1–6 384)
3. Gender of the respondent (M/F)
4. Age and birth year (requested)
5. Education (requested)
6. Profession (requested)
7. Place of residence (requested)
8. Year or years of cancer experience
9. Age when becoming a cancer patient
10. The original cancer patient(s)
11. Cancer type(s)

To create the general database, I listed the most significant themes and possible further research topics in my research diary, which is helpful in recalling the whole interpretation

process. In addition I made several files for reference on different themes, such as: medical personnel, oral history of cancer, dreams and predictions, the aetiology of cancer, meaningful tropes, writing and its significance, remedies, patients' roles, sexuality and physiological changes. In addition I made a reference file that was titled "to consider". This file included cancer patients' general notions about life, death and being a cancer patient.

The aim of such a careful analysis is to discover the general (most often repeated) constructions that derive from the primary content, themes and issues (Uotinen 2008, 142–143). Thus, my assumption is that the general constructions are connected to culture-bound ideas, and that this affect peoples' reasoning and decision making in everyday life, as well as when writing down their life-experience, the resulting texts having an ethnographic, and thus a primary, value for the folklorist.

The process of pre-selecting themes for this thesis was by no means easy as the short pathographies sometimes cover a participant's whole lifespan. The selection process could at best be described as handling the texts, at first with a horse-rake, then with a rake and then more carefully with a comb, without letting the whole field out of sight. Initially I picked out the three main themes tackled in this work: metaphoric expressions, dream narratives and accounts dealing with ethnomedical issues, such as personal illness aetiology and alternative or complementary means of cure. At that point, I did not have an idea how, and in what context, I would interpret these accounts.

When reading the texts I also became interested in accounts that reflected respondents' ideas about their roles as cancer patients, both in the social context as well as in the medical. These textual units were bound with argumentation dealing with self-alteration and personal identity. As these topics are also connected with patients' physical alterations and feelings (see Chapter 7), I made a methodological decision to avoid the current approach in social sciences that deals with the phenomenology of the body introduced by philosopher Maurice Merleau-Ponty (Merleau-Ponty 1962). This decision was based on my internal discussion as a folklorist, leading to the conclusion that, based on these pathographies, it is almost impossible to access patients' embodied memories accurately. In my view, written texts are interpretative by their nature and thus too far from embodied experience. As the question of embodied experience was not raised in the archival request, it felt too artificial to make statements in this direction.

I also asked myself several times what the meaning of illness is and how it is expressed in the pathographies under study. This question lead quite often to two further subjects: the



general quality of life and death. I recognised the deep connection between the two concepts: cancer and death, and the carefully collected accounts dealing with death and dying. Despite patients' concerns regarding death and dying, the careful reading of cancer narratives also demonstrates that patients have a general need for reassurance and that there is life with, and after, cancer. Thus, although there is plenty of material dealing with cancer patients' concerns in this direction, I decided to select the issues dealing with living and being alive and re-thinking the meaning of illness in different situations for further research.

Apparently, rejecting some narratives and thematic issues is a part of the selection process. During the reading process I realised that some narratives and themes were more interesting for me than others. The more interesting themes are those connected with cultural expectation and popular thought about cancer. Some texts, on the other hand, were less valuable for the task of preparing this thesis. This was true of texts relating to the illness of children; equally problematic were long detailed descriptions of hospital procedures and stories that were too self-centred, describing only individual sorrow and suffering. After examining the texts I soon recognised that it would not be fruitful to analyse them in my research as there were no answers to my primary research questions. Whatever other merits these texts may have, for my purposes they somewhat lacked the necessary context in relation to the cultural phenomena under investigation. I chose texts that allowed the requisite distance to be created for objective observation, without being either too emotional or too critical.

## **Problems with the presentation of the research results**

The content analysis that I employed to select the research materials for this work obliges the creation of certain generalised models in order to represent the results and argumentation of the research. Dealing with a text corpus based on the results of a writing competition creates several problems in this regard. In the cancer narratives, the respondents' individual observations follow the psychological process of coping with serious illness and accepting the idea of having cancer. As I shall point out in the following chapters, for many people, adopting the cancer patient's role has a central significance. Compared to 'normal' life, the cancer patient's role means that individual decision making and personal life is abruptly interrupted. In their writing, participants describe how, by

putting on hospital clothes, they lose control of their lives and thus, for many respondents, the period of being a cancer patient and being treated in hospital signifies the unfortunate loss of personal identity. For cancer patients, the crisis caused by their illness signifies a painful period of self-alteration. Thus, the central task of the cancer narrative is to describe the individual cancer experience in order to remember, analyse and communicate the lived experience. This means that despite constantly reappearing themes, cancer narratives are by no means identical.

On the other hand, in everyday life cancer patients are forced to fight popular expectations, like beliefs that being diagnosed with cancer equals fading and passing away. This means that, in addition to individual concerns, all participants emphasise in their responses culturally and socially important issues, showing that the respondents share 'truthful' information about the cultural meaning of cancer and its consequences. Regarding people who participate in writing competitions, Satu Apo has proposed that participants identify themselves as creators of scientifically valuable resources (Apo 2001, 19). Therefore, despite the subjective experiences analysed in the writing, all respondents are aware of their role as the producers of ethnographically important material.

Cancer narrative forms a large and heterogeneous text corpus, which at best suits the detection of different perspectives (Pöysä 2008, 238–240, Apo 2001, 17). Therefore, it is challenging to find the appropriate analytical categories with which to display both the individual concerns of cancer patients and culture-bound cancer discourse. On the subject of the themes discussed in this cancer narratives thesis, I do not wish to propose any cultural models of human illness behaviour as cognitive scientists have attempted (Holland & Quinn 1987). I am, above all, interested in tradition, which Lauri Honko has called "the stuff out of which cultures are made and which we have deposited in our folklore archives" (Honko 1988, 9). In the current context this refers to the ideas that people share (culture-bound cancer discourse) while analysing cancer's significance in their lives.

The available materials create a certain space that becomes the model of culture, and the various connections that form the structure of this model are identical to traditional understanding of a particular situation (Lotman 2006, 78). In narrative-based research this means carefully studying narrative structures, episodes, expressions and word use in order to understand what is expressed.

The culturally bound ideas deriving from and representing the cancer discourse are like any popular set of ideas that are heterogeneous and even contradictory. Quite often this means that in different texts the same ideas may be expressed and yet emphasise different

things. Thus, the attempts to put such tradition into some kind of a model would end with one-sided, analytical categories that have no significance outside the particular study. Tuulikki Kurki has proposed that any analytical model represents only a researcher's abstraction based on the source material (Kurki 1996, 23–24, see also Apo 2001, 28–31). This critical assumption suggests that it is difficult to aim for any scientifically accurate categories where culturally bound ideas and traditions are concerned. For the researcher, this gives the possibility only to read, compare and make comments when trying to map a particular tradition using his or her intuition. Such intuition-based study does not reduce the validity of research, but rather makes it more human (Hatakka 2004, 176). Hatakka's statement regarding the human approach in interpreting written texts is crucial, because cancer narratives exclusively reflect the participants need to be listened to, heard, and understood (see also Apo 1995, 37).

Considering the problem of modelling a large text corpus, Satu Apo and Veikko Pietilä have suggested that to support the researcher's arguments it is important to use sufficient examples (Apo 1990, 65; Pietilä 1976, 174). Using small text units as examples of participants' argumentation or personal 'voicing' has become a generally accepted method of qualitative content analysis, which I shall implement in this thesis. However, I point out that the main focus, when giving such examples as glimpses of general tendencies in the text corpus, must still be on the thematic whole and the contextual field that the particular unit derives from (Uotinen 2008, 141). As the whole narrative contains various textual dimensions (see Chapter 4), the single textual unit is inseparable from the general tendencies of the narrative. We must bear in mind that the general text corpus, with its values and characteristic features, also has significance in terms of understanding the aims and tendencies of the given examples.

In order to secure lasting contact between the original text and the text example, reference to the original texts must be accurate. This is also the reason why I use the original texts within the analysis, with English translations given in support only because this is an English language thesis. In fact, the translation of Finnish texts into English creates many problems. The sentences in the original texts are typically in the passive mode and thus difficult to understand for English-speaking readers. Additionally, when considering certain words and expressions, problems occur with different connotations. A prime example is the Finnish word *syöpä* (the eater) which demonstrates how one word may derive associations that are markedly different to the common English word 'cancer'.

Therefore, the original Finnish quotes or expressions come ahead of their English translations.

The need to operate between complete texts and textual segments is influenced by Mikhail Bakhtin's suggestion regarding the understanding, or 'reading', of thematic narratives. Applying Bakhtin's ideas, cancer narratives (as wholes) represent the secondary (complex) speech genres that absorb the primary (simple) genres. In his study on speech genres Bakhtin has emphasised that, "if we aim to understand any essential system of ideas, or more precisely the nature of utterance, it should be revealed and defined by analysing both types of speech genres" (Bakhtin 1986, 61). Considering this notion, I begin this thesis by analysing the narratives as wholes before turning back to the wider culture-bound context, then later moving further to analyse the primary genres employed in cancer narratives. The cancer narratives selected for textual analysis as wholes appear in Chapter 4. I hope they give readers a good opportunity to compare my arguments with the ideas deriving from reading respondents' own writing.

## **Evaluation of the available sources**

On the one hand, thematic narratives mediate personal experience as the composed texts cover the significant events of individual life-history. On the other hand, such topic-centred (autobiographical) narratives form an excellent source for the study of socially and culturally defined discourse in a particular context. In recent years several Finnish scholars have proven that thematic writing dealing with personal experience is an excellent source for a folkloristic approach. For the particular scholarly approach that in Finland is called *muistietotutkimus*, the thematic narratives represent the results of historic and cultural processes merging with (secondary) knowledge and social activities (Fingerroos & Peltonen 2006, 12f.). Here, at the centre of the researchers' attention, is the communicative value of the text. It does not matter if the text is oral or written, what matters is what is told and how it is told, and perhaps one should not forget the aspects that stay untold for the same reasons. Accordingly, Ulla-Maija Peltonen has claimed that such text-based knowledge allows the acquisition of more information about historical and cultural variation regarding the construction of social reality and its interpretation (Peltonen 2006, 112). Regarding cancer patients' pathographies, this means the shedding of light on

personal emotions, thoughts and experiences in order to challenge the official knowledge mediated by pathologies and statistics containing cancer survival rates.

In order to evaluate cancer narratives as research material, and to understand their communicative value, it is important to note that everyday events in human life cannot become narratives without cognition, interpretation, and meaningful references to personal experience. The German folklorist Albrecht Lehmann, who has since the 1980s studied *alltägliches erzählen* (everyday narration) among Germans, has introduced his theory on everyday narration as a path for *bewusstseinsanalyse* (consciousness analysis). In his book *Reden über Erfahrung* (2007) he used various approaches to point out that if we discuss the narrative creation process it is impossible to differentiate between *erinnerung* (reminiscences) and fiction occurring in narratives. Considering the narratives analysed in this study, this is an essential statement. It points out that to evaluate the available materials it is important to examine the connections between experience, memorising, verbalisation and narration.

Lived experiences are by no means narratives on their own. Only through the verbalisation process is experience changed into narrative and accordingly the narrative becomes an act that breaks the silence on an individual level: due to narration personal experience becomes meaningful. Individually meaningful narratives have particular tendencies. To make his or her point a narrator must make a synopsis of events, even if he or she aims to compose a ‘truthful’ description of lived events. Despite the desire for accuracy, narrators are unable to express everything that has taken place in life. This also means that the reader of these texts cannot perceive the amount of untold events. The unverballed experience stays unapproachable, but to acknowledge this means accepting the idea of narratives as fictive representations of true events.

While studying thematic narratives it is important to have in mind that the process of composing a narrative is a thoroughly selective one, influenced by multiple frameworks, although the narrative as we first receive it seem to be mediating ‘reality’ (Apo 1995, 139–140). People select themes and issues that are important in the light of their personal cancer experience, but to be objective, they also search for words, expressions, themes and events that make a good and meaningful narrative. This is because people are familiar with the narrative schemata and general means of creating a narrative; however, not all people have qualities such as verbal expression or writing skills with which to create a coherent and perhaps even entertaining narrative, although archival requests demonstrate some demand

relating to the literary qualities of collected texts, mainly by calling these activities writing competitions.

Folkloristic studies of narrative and narration have lead to an understanding that in narrating, people firstly express experiences, values, concerns and ideas important to them as individuals or collectives, and, secondly, they do so through the employment of stylistic techniques, tropes, tones of voice and gestures (Klein 2006, 14; Kaivola-Bregenhøj 1996, 24–30; see also Stahl 1977, 17). Like oral performance, written self-expression is also influenced by an active selection-making process that is affected by individual ability to remember and verbalise the rules of written self-expression. This means that all available writing is affected by individual self-expression skills and the aims of the participant. As it appears in letters appended to the cancer narratives, the process of writing down individual experiences is by no means an easy one:

*Olen tässä kirjoittanut elämäni tosiasioita 7 vuoden ajalta, pörröttänyt niin kuin lankakerää. Kaikki vaiheet pysyy mielessäni elämän iltaan asti. Kirjoitusvirheitä on tullut, mutta ne kai annetaan anteeksi. Kirjoituskonetta ei minulla ole. Onpahan nyt asiat paperilla kynällä töherrettynä, jos näillä on jotain merkitystä jollekin...*

I have written about the life truths from the past seven years, spinning them as a yarn. All phases will stay in my mind until the end of my life. I have made writing mistakes, but I suppose they will be excused. I have no typewriter. I have smeared things onto the paper with pencil, hope they have some significance to someone... (267)

For folkloric study of narratives and narration, identifying the genre and its qualities is equally important for accurate interpretation. The American anthropologist William Hanks has suggested that “genres derive their thematic organisation from the interplay between systems of social value, linguistic conversation, and the world portrayed. They derive their particular reality from their relation to particular linguistic acts, of which they are both the products and the primary resources” (Hanks 1987, 671). In the current context it is significant that different illness narratives may have different culturally set qualities, mainly dependent on the particular discourse. Thus, to be interpreted according to the generic value emphasised by Hanks, narratives must gain a certain degree of ‘finalisation’ (Bakhtin 1986, 76). This means that if someone desires to share some significant aspect of his or her life, he or she must ‘fix’ the experience in the culturally appropriate model of narrative.

The degree of ‘finalisation’ characteristic to the cancer narrative is problematic as the extent of coherence, meaning, and emotional input in these narratives is foremost dependent on a participant’s skills in written self-expression. The majority of the analysed cancer narratives contain neither the “value of verbal art” (Bauman 1984, 30) nor the assessment of written, presumably poetic, literary text (Todorov 1977, 113). This lack of poetic or literary qualities or style is certainly not a fault. According to some researchers, it is an important aspect that tells its ‘readers’ that thematic writing concerning personal experience stands in between the oral and the written traditions (Apo 1995, 173–186; Peltonen 1996, 60–134, Pöysä 1997, 33–56, Salmi-Niklander 2004, 36–39). However, I do want to suggest that thematic writing should be seen as a unique genre with a specific written quality (see also Hatakka 2004, 173). Despite the lack of finalisation typical to oral or literary narratives, cancer narratives as thematic accounts may be approached as a whole that creates valuable context for use analysing the primary genres that occur within the texts (see Chapters 4, 6 and 9).

Considering human life, illness experience and everyday narration, Albrecht Lehmann has suggested that, unlike other illnesses, a heart attack or cancer signifies a borderline situation in personal life, and therefore narratives dealing with lethal illnesses differ from other illness narratives (Lehmann 2007, 198). The cancer narratives analysed in this work indicate that most typically the respondents examine their own life patterns after they became affected by cancer (Drakos 2006, 134f.). The times lived before appear less significant, and are discussed mainly in connection with the origin of the illness. Considering the material at hand, I would like to emphasise that even though ‘normal’ life (apparently) stops with the cancer diagnosis, individual lives continue to be full of everyday concerns and unexpected situations. One respondent rather wittily mentioned that: *“Ei syöpä kenestäkään enkeliä tee, ei ainakaan eläessään!”* “Cancer will not make you an angel, at least not as long as you stay alive!” (549) I find this brief notion is highly suitable to describe the amount of (thematic) variation present in cancer patients’ lives, of which cognition, reminiscence, verbalisation, and narrative composition process influence the quality of the final outcome.

## 2 Cancer Narratives as Ethnographic Sources

The cancer narratives analysed in the current work are the results of the writing process. Even if the respondents have tried to compose a coherent and meaningful story, full of emotional turns, only a few of them succeeded in doing so. Adopting the suggestion made by Dell Hymes, the American sociolinguist, the process of composing thematic writing is comparable with oral performance, where everyone can speak, but only few have communicative skills suitable for entertainment (Hymes 1974, 75). From the stylistic point of view, written cancer narratives stand between the oral and written tradition of self-expression. The letters that accompany the cancer narratives express the fact that, on the one hand respondents tried to describe the events experienced as accurately as they appeared in everyday life (060, 569), while on the other hand, they were aware that over time the painful experience faded in their memory, so they cannot be entirely accurate (099, 101, 354, 363, 396, 507, etc.). The writing process itself is also complicated as it forces the participants to choose between relevant and irrelevant themes (236, 267, 397, 401, etc.). For this study, however, the literary quality of the texts is not important; more important are the facts preserved by the cancer narratives, via the writing competition, and the fact that this creates a context that represents popular ideas regarding cancer that mediate the everyday life of Finnish cancer patients. Therefore, I approach the cancer narratives as ethnographic texts, which according to Mikhail Bakhtin, are definable as “literary but extra-artistic authorial speech” (Bakhtin 1981, 262). In my opinion the characteristic ‘extra-artistic’ does not diminish the value of cancer narratives as an ethnographic source, while the collected writing allows study of the cancer experience on the individual, sociocultural and societal level using the narrative approach.

Cancer patients’ narratives about their illness may be approached as “basically believable” and “near” to individual experience (Garro & Mattingly 2000, 260; see also Goldstein 2004, 157–177). Therefore, I wish to analyse the narrative composition as a series of choices influenced by numerous internal and external aspects. Firstly, the individual “verbalisation” or “textualisation” process is affected by an individual’s ability to memorise and remember (Lehmann 2007, 50–57; Honko 1998, 59; Lord 1987, 307). Secondly, people select events and episodes from among the vast range of possibilities in the flow of experience, and then present them in an order which itself intentionally or



unintentionally conveys significance (Garro & Mattingly 2000, 260). Thirdly, narratives as representations always contain some kind of particular goal (Jakobson 1960, 351), and carry certain culturally defined functions (Bascom 1954, 337–338) as well as individual intentions affected by the context (Siikala 1990, 90–91). To demonstrate the value of cancer narratives as a research object, it is important to examine the rules of narration, which affect the construction of thematic writing, and analyse the possible influence of the individual and sociocultural aspects that influence the composition of narratives.

## The motivation to write

The written manner of self-expression is very common among Finns (Salmi-Niklander 2004, 42–44). Since writing skills were introduced to Finland, the preservation of personal memories and experience has become a part of everyday life (Makkonen 2002, 9–11). Because of the historical practice of collecting oral tradition, Finns are used to participating in the writing competitions organised by folklore archives (Pöysä 2008, 223–228). However, written individual experiences and reminiscences have only been accepted among ethnographic sources recently. Not too long ago, such materials were evaluated by folklorists as a nuisance to folklore archives (Latvala 2005, 27). Today the situation and attitudes have changed, and written (not only autobiographical) narratives have gained high value among Finnish folklorists as ethnographic sources dealing with personal experience.

I would like to discuss the respondents' motivations for writing and contributing their experience to the archives. The writing competition is only secondarily important for writing down personally significant experience, thoughts and feelings. Of far more importance has been the opportunity to 'talk' about multiple issues relating to cancer as it is experienced by individuals:

*Olen myös kiitollinen tämän keräyksen järjestäjille, sillä he antoivat minulle sysäyksen ryhtyä kirjoittamaan, Olen nyt ensimmäistä kertaa seurannut yhtä sävellystä 'elämäni' johdonmukaisesti läpi yhden soittimen – syöpä – osalta. Partituurin tutkiminen on ollut raskasta mutta hyvin antoisaa. Olen päässyt lähemmäs itseäni ja löytänyt paljon yllättäviäkin sävelkuvia.*

I am also grateful to the organisers of this competition because they gave me a reason to write. This is the first time I have analysed one composition in my life through one

instrument – cancer. Studying the text has been a hard, but very giving, experience. I have become closer to myself and discovered many surprising things about myself. (202)

*On ihan hyvä, että tällainen kirjallinen “mitä kuuluu” kysely on järjestetty. Minä ainakin olen paperille paljastanut nyt sellaisia tunteja itsestäni joita en keskusteluissa ystävillekään kerro. Kaikkia kipeimpiä edellä kerrottuja tuskin vaimollekaan. En ainakaan tässä vaiheessa. Meillä on luottamukselliset välit, mutta yritän säästää häntä sellaiselta mikä sattuu eikä ole välttämätöntä kerrottavaksi.*

It is really good that this kind of ‘how are you’ exploration has been organised. I have revealed in the paper the kinds of feelings about myself that I do not go into when talking with friends. Most of the painful memories I have hardly told my wife. At least not yet. We trust each other, but I try to save her from things that are not necessary to tell. (508)

*Oheiset liuskani ovat kooste vuosien varrelta erilaisista muistiinpanoista. Olen liian väsynyt jaksakseni kirjoittaa niitä kaunokirjallisempaan muotoon. Haluan vain tuoda julki elämässäni päällimmäisenä olevan tuskan ja liian raskaat päivät, jotta tekstini tulisi mahdollisesti palvelemaan ja ehkä estämään ketään muuta joutumasta samanlaiseen kurimukseen.*

The following pages are a summary of different notes made during past years. I have been too tired to write them in a more literary style. I just want to bring out the spleen ruling my life and my too-hard days, so that perhaps the text can prevent others from ending up in similar torture. (363)

Participants said that writing is a good way of expressing oneself. Therefore they began to make notes about their illness experience while still in hospital. Such writing becomes a way to keep track of daily concerns in a situation that is affected by physical sufferings and inner confusion. Thus, respondents say that the act of writing helped them to clear their thoughts and bring structure to “the mess in one’s head” caused by the illness: “*Mutta teki hyvää kirjoittaa. Nyt sitä voisi taas jatkaa – omaksi iloksi.*” “Writing made me feel good. Now I could continue with it – just for my own benefit” (334). Or, “*Ellen osaisi kirjoittaa tunteitani ulos en tiedä montako astiaa olisi särkynyt. Kynät ovat sentään astioita halvempia ostaa.*” “If I could not express my feelings in the written manner, who knows how many dishes would be broken. Buying pencils is anyhow cheaper than buying dishes” (381).

Writing down experiences and thoughts also aids the memory. The inner confusion (caused by illness) may be so great that everyday life and events just slip away.

Respondents who said they kept a diary regularly, wrote that in some stages of the illness process it was difficult to concentrate on writing, meaning that the physical and psychological suffering caused by cancer made people silent:

*Päiväkirjoistani (pidän päiväkirjaa yhä) siltä ajalta en löydä ainuttakaan merkintää. Ajalta, jolloin olin menettää äitini, on kuin vuotta 1986 en niiden mukaan olisi elänytkaan.* (085)

From my diaries (I still keep a diary) of that period I find no entries. At the time I was about to lose my mother, I did not exist in 1986 according to the diaries. (085)

*Muistikirjassani on kahdeksan päivän valkoinen väli. Sen ajan sivuilta löydän yhden sanan, piinaviikko. Sana kaikkineen kuvaa näitä hivuttavan tuskan täyttämiä päiviä. Ajatukset kiersivät samaa harmaata rataa. En tiennyt mitä tehdä, miten olla. Olin kuin naulittu olevaan tilaan.*

In my calendar is a white gap of eight days. From the pages of this period I found only one phrase: “a torture week”. These words apparently described all those days, filled with spleen. Ideas whirled along the same grey path. I did not know how to be or what to do. I was, like, pegged into this situation. (101)

For many participants, one of the motivations for sharing individual experiences was the fact that they wanted to help and support other cancer patients (194, 260, 354, 390, etc.). Despite the fact that, according to sociocultural expectations cancer signifies only negative experiences, for many writers the individual experience proved to be empowering in many ways. Linda M. Hunt, an American anthropologist who has analysed the illness stories of Mexican cancer patients, has produced similar results. She has noted by the same token that in the course of rebuilding a workable image of themselves, the world, and their place in it, patients generate narratives that forge an identity around patient-hood in ways that negotiate issues of social empowerment (Hunt 2000, 92). The ideas presented in Finnish cancer patients’ writing support Hunt’s statement, revealing that despite its devastating impact in many ways, cancer changes patients’ lives to become more positive by opening new perspectives and possibilities: “*Nyt – jälkeenpäin – olen kiitollinen tästä syöpäkokemuksestani. Se kypsytti minua ihmisenä. Vaikea sairauskin voi olla elämää rikastuttava kokemus!*” “Now – afterwards – I am grateful for this cancer experience. It changed me as a person. A serious illness can also be an life enriching experience” (079). Another respondent has even used rhyme to express this feeling (090):

Niin kaartuu ihmisen elämänsaari,  
syöpäkin voi olla siinä saari,  
josta nousee ilon elämänpuu,  
jonka voimalla sydän avautuu  
kokemaan, mitä on onni, autuus,  
elämä, kaikki sen salaisuus.

So bends the human lifebow,  
where even cancer can be an island,  
where grows the life-tree of joy,  
which has the power to open up hearts,  
to experience, what is happiness, beatitude,  
life with its all secrets.

Respondents wish to express the fact that, despite cancer, their lives continue. Compared to other situations, their individual sorrow and suffering can only be minor:

*Opettihan sairaus myös muistamaan, että mikään tässä elämässä ei ole itsestään selvää ja tänään on loppuelämämme ensimmäinen päivä. Tämä on järkyttävällä, mykistävällä tavalla tullut todeksi kirjoitaessani tätä 28.9.94 jolloin autolautta Estonia upposi Utön lähietäällä ja yli 800 ihmistä hukkui. Se on ollut niin valtava shokki, että sitä ei vielä pysty täysin tajumaan ja tietoa sulattamaan.*

The illness taught me to keep in mind that nothing in this life is self-evident and today is the first day of our remaining life. This has become evident in a shocking, silencing way as I write this on 28.9.94, when the Estonia ship sank near Utö and more than 800 people drowned with it. This has been such a great shock that one cannot really understand it and digest the knowledge. (265)

However, to attain such understanding needs time, certain personal qualities, motivation and support, and so composing a personal cancer narrative may be helpful in reaching such conclusions. In his significant essay *Life in Quest of Narrative*, Paul Ricoeur has stated that composing a lifeworld is a mediation between man and world (referentiality), between man and man (communicability) and between man and himself (self-understanding) (Ricoeur 1991, 27–28). Because of various levels of dialogic imagery present in cancer patients' writing, the narratives also tackle, in addition to the illness experience, several other important aspects connected to human life: everyday living, family and work, human relationships and other meaningful themes that have gained significance during the respondents' lives:

*Mitä enemmän olen aina tutkinut kirjoitelmaani, sitä enemmän on tuolla aivojen takaosassa ruvennut kytämään kauhea tietoisuus, että se on aivan väärin kirjoitettu!*

*Kirjoitan aiheesta "Kun sairastuin syöpään." Ja mitä minä teen! Kirjoitan laveasti Lappohjasta, koulusta, keilauksesta, perheestä jne. Toivoton tapaus!*

The more I have studied my writing, the more I get the terrible feeling in my head that this is written totally in the wrong manner. I write about the theme, "when I fell ill with cancer" and what do I do? I talk about northern Lapland, school, bowling, family, etc. A hopeless case! (060)

Participants composed their writing in the hope of offering a different interpretation of the cancer experience and thus confront the socioculturally agreed image. The given motivations for writing point out that in the cancer narratives the respondent's desire to share the cancer experience is mediated somewhat differently because it is without the fear of being (mis)judged by society. Discussing the meaning of writing compared to oral communications, Paul Ricoeur has remarked that issues that become fixed by writing represent a discourse that could be spoken, but become presented in writing because they are not, nor can they be, communicated orally. Considering the meaning of writing from the cancer patient's point of view, the following statement from Ricoeur is crucial: "Fixation by writing takes the very place of speech, occurring at the site where speech could have emerged" (Ricoeur 1981, 146). This statement helps us to interpret and point out the main reasons why people choose to write about their illness experience. Firstly, writing is a possibility for self-expression. Secondly, people write instead of speaking because they feel that it is not acceptable to share their cancer experience in oral communication. Thirdly, composing a narrative allows mediation of the individual experience in the desired way, thus writing functions as meaningful for writers and at the same time formulates a particular experience for their readers.

Consequently, the main motivation for composing cancer narratives may be interpreted as the cancer patient's desire to receive some responsive understanding from other people, and to receive this from institutions that are unfamiliar with the cancer experience and its meaning on the individual level. Where such understanding appears unachievable in everyday communication, writing becomes an alternative path.

## **Inner narrative**

Sigmund Freud began to approach and analyse his patients based on their narratives, and since that time many psychologists and sociologists have suggested that one possible

method of identity alteration is by renewing one's lifestory (Brockmeier 1997, 178). It is, of course, a debatable assumption that everyone has a lifestory and that illness does indeed become interpreted as the crucial event that makes us re-examine our existence. We must bear in mind that only the verbalisation and interpretation of bodily events makes one's life a narrative, not the events themselves, and not everyone is eager to interpret his or her own life.

Concerning health and illness, the socioculturally accepted idea is that if we take care of our bodily condition and follow culturally accepted norms, we stay healthy. In everyday life many people experience a mismatch between such a belief and personal health. In particular, people with cancer suddenly notice that 'health' has turned to 'illness'. We may ask how, in such a situation, is one's life influenced if the feeling of fitness is lost and reality confronts personal identity within a changed social setting (Jacobson-Widding 1983, 14)? To become a part of a renewed social setting, or illness discourse, the individual has to adopt new roles, such as that of patient, and learn a new vocabulary in order to discuss the illness and its treatments. The illness also influences an individual's social and economic situation. Therefore, a person who is ill, is often forced to adapt his or her past behaviour and activities because of a radically changed physical condition or social position, and to find new meanings with which to continue life (Mathieson & Stam 1995, 283–306). On an individual level, the period of falling ill and of being ill is full of alterations, questions and hesitations, and may be approached as an inner negotiation process.

Linda Hunt has proposed that having cancer requires mobilisation of resources for treatment, eliciting assistance for patient care, and renegotiation of the patient's privileges and obligations within familiar and other social hierarchies. Therefore, shifts in a person's identity when he or she has cancer, emerge in the context of the larger social framework, subsuming questions of domination and subordination (Hunt 2000, 91). This is a complex process of evaluation that may be completed in different ways, such as climbing a mountain, if physical condition and treatment allow, taking a year off work, finding a religious road, painting a picture, etc. There are several possible ways in which to renegotiate the self in an appropriate way, depending on the course of the illness and its impact on an individual's life.

Above all the inner negotiation process is an imaginary dialogue between the individual and the self. This is a dynamic process, as the individual, as well as the social, aspects have ongoing effects on people and their lives. The Finnish sociologist Vilma Hänninen has

written that people's inner negotiation process is affected by a situation that is constantly in alteration. The situation not only changes if people act, it also changes if they do not. The situation is based on facts, and thinking or acting may not change it, although the situation may be interpreted in various ways (Hänninen 2000, 21–22). The person suffering from a serious illness (willing or not) is challenged to examine his or her life before the illness, and accordingly he or she must negotiate the outcome of their particular findings. An individual's ability, and will, to analyse and interpret the constantly changing situations of the illness experience, affects the process of negotiation with the self and the (possible) formation of the inner narrative.

We may suppose that the process of self-understanding, or inner negotiation, initially takes place in pre-narratives that are composed, and exist in their complexity, in human minds. Pre-narratives, or inner narratives, are understood as a process in which the person interprets the events of life relative to the opportunities offered by the current situation. For example, Vilma Hänninen has defined inner narrative (*sisäinen tarina*) as a complex process in which the general and individual, symbolic and material, linguistic and non-linguistic, public and private, meet, and in which new meanings are given (Hänninen 2000, 21). If we agree that such inner narratives exist, it is important to point out their difference in comparison to written narratives.

The main problem here seems to be with grasping the inner narrative. How do we, as outsiders, gain access to information preserved in inner narratives? This seems impossible without having people expressing their inner feelings, which again is an entirely different situation. Although the cancer patients analysed here demonstrate that during the writing process the inner negotiation process continues, written self-expression has to be approached as a public performance. Even if the externalisation of memory may be a purely internal process, from the moment we articulate or write, we express our experiences and memories, and therefore we communicate with others (Fentress & Wickham 1992, 26). Accordingly, written texts, unlike inner narratives, correspond to the public speech act, and thus are invariably influenced by various expectations arising from the subject of cancer and from self-expression in the written manner. When analysing such materials, it is important to bear in mind the fact that writing is composed with regard for potential readers. Because writing becomes the opportunity to share individual knowledge, experience and feelings with others, it is a significant continuation of the inner negotiation process.

## The cancer narrative as a key narrative

When composing a narrative, people verbalise their experience for themselves and for others. The expressive value relating to the course of an individual's illness makes cancer narratives "individually intentional" (Bakhtin 1981, 289). In Finnish culture, having cancer is strongly connected with images of death and dying, and this means that cancer patients' writing is, in many ways, influenced by this culturally accepted idea. We may suggest that the cancer experience divides the individual lifestory into two periods – before and after. If cancer is considered a dominant event in a person's life, then cancer narratives may be viewed as plots in which cancer-related experience generates the "key narrative" (Lehmann 2007, 198). Because of its fatal influence on human life, the process of falling ill with a life-threatening illness is as significant as the experiences of war, deportation, emigration, and other pivotal events common to the human experience. In cancer narratives, particularly when playing the culturally stigmatised cancer patient's role, people are forced into a situation in which personal identity becomes loose in various ways. The cultural stigma of cancer puts cancer patients under psychological pressure. Biomedical treatments add physical suffering, while at the same time leaving patients alone with their individual concerns. The Finnish folklorist Annikki Kaivola-Begenhøj has implied that one person may have several key narratives, although the experience of losing control of one's own life is understandably one that can never be forgotten (Kaivola-Begenhøj 2006, 41). Individual sorrow at hearing the diagnosis of cancer, and the struggle of regaining control over one's life, could be defined as the central issues in cancer patients' key narratives.

Because of cancer's lethal image, cancer key narratives may be described as following the inner negotiation process in which the sufferer becomes familiar with the idea of dying:

*Olin kokenut selvän lähtölaskentani alkaneen siitä hetkestä, kun sain tiedon syövästä. Aikaisemmin kokemani vaikeat sairaudet olivat jo opettaneet minulle paljon, mutta ne eivät olleet sillä tavoin henkeä uhkaavia kuin syöpä.*

I felt that a countdown began when I heard about cancer. The serious illnesses that I had experienced before had already taught me a lot, but these were not in that way as life-threatening as cancer. (331)



According to the model proposed by Swiss-born psychiatrist Elisabeth Kübler-Ross, this process includes the phases of shock, denial, anger, trade, depression and finally acceptance (Kübler-Ross, 1973; see also Myllykoski 1981, 38). The model, presenting the inner negotiation process characteristic to people with a lethal disease, is well suited to the construction of a basic structural model for the cancer narratives under observation here.

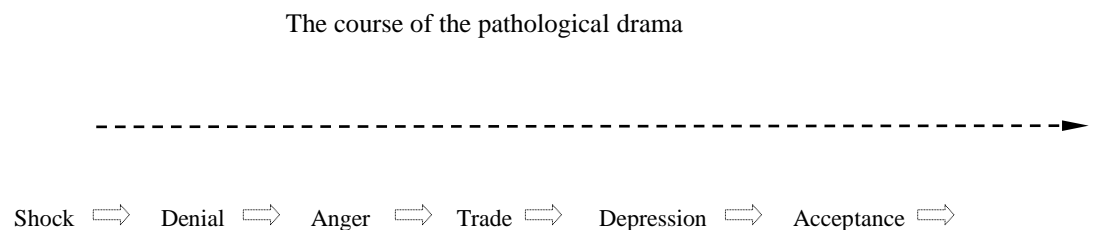


Figure 10. The stages of inner negotiation

In life, of course, all analytical models have secondary importance. The American physician and anthropologist Arthur Kleinman has demonstrated that in Western society the person with cancer continuously returns to the idea of dying in changing situations (Kleinman 1988, 147–149). According to the writing analysed here, people experience phases of shock, denial, anger, trade, depression and acceptance repeatedly; meaning that in the inner narrative, accepting the idea of dying must be continuously negotiated. Cancer narratives reflecting selected parts of the inner narrative demonstrate that when being confronted with a fatal illness it takes time to reach a point where a person accepts that life will not last forever. Furthermore, even if people accept having cancer or being terminally ill, it does not mean that they stop fighting for their lives. Typical to key narratives is the understanding that people reach about how to cope. This kind of awareness makes people more tolerant and unwearied:

*Syöpää ei voi koskaan unohtaa, se seuraa mukana selkärepussa koko elämän. Mutta sinuksi tuleminen sairautensa kanssa on tärkeä asia, mutta aikaa vievä prosessi. Jatkuva muisto on fyysinen puute/erilaisuus, en ole enää koskaan sama minä. Enkä ihmisenä ole sama, kuin olin ennen syöpää. Tällä en tarkoita että se olisi pelkästään huono asia. Todellinen kasvunpaikka tämä sairaus on ollut. Elämässä on usein vaihtoehtoja valita elämänpolkuja. Sairastuessaan ei paljon tarjoilla mahdollisuuksia ja vaihtoehtoja, on otettava vastaan mitä tulevan pitää. Haluisi tai ei.*

I can never forget cancer as it follows me in the rucksack all my life. Coping with illness is an important thing, but it takes time. The continuous memory is the physical difference,

as I will never be the same. In addition, as an individual I will not be as I was before I fell ill with cancer. I do not mean that this would only be a bad place. This illness has been a reason for growth. There are often possibilities and opportunities available along the life path. When ill there are not many possibilities or opportunities, one must accept what is given. It does not matter if you want to or not. (046)

This example demonstrates that although people cope with the idea of having cancer they will always carry this experience in their minds. This leads us to the following issue affecting the composition of cancer narratives, namely, the question of remembering and memory.

## Remembering and memory

Writing a narrative is closely associated with the process of remembering and memory. At the time that psychologist Endel Tulving first introduced the types of episodic and semantic memory that relate to human action (Tulving 2002, 3–5), many folklorists were interested in memory and its impact on the narrative process. For a while, division between different memory types became predominantly attractive in narrative research. This approach was foremost employed to follow the processes by which personal experience was turned into collective tradition. It was an attempt to explain how an individual experience is altered by the collective tradition, and formed into a folklore product. Accordingly, in the folkloristic approach, remembering became interpreted as a social event in which reminiscence is simultaneously affected by various factors, not only the psychological regularities related to remembering (Chafe 1977, 220–224, Siikala 1990, 111–112).

In recent years, mainly since the shift to autobiographical narratives, the interest of folklorists has moved towards memories and reminiscences as a folklore genre. The Finnish word *muistitieto* (lit: ‘memory data’) refers to remembered knowledge (Fingerroos & Peltonen 2008, 8). Unfortunately, the affect of episodic or selective memory on the narration process has been left to some extent without attention in this context. The individual ability to remember has a crucial role in narrating past events, while it makes possible a mental journey by ‘bending’ time’s linearly moving arrow into a loop (Tulving 2002, 2). Particularly in critical situations, in which the self is loose or even lost, an individual’s ability to remember and memorise is different, and thus significant in

interpreting the formation of key narratives and the individual narration concerning cancer experiences.

The capacity of working memory is limited and so people select and organise their knowledge into mental units. As a result, some of the events we experience disappear, others are recallable and some stay vivid forever (Ericsson & Kintsch 1995, 211f.). According to the material at hand, the respondents feel differently about their individual abilities to remember various cancer-related events. This means that their conscious awareness regarding past events, and recalling them, is very different, which naturally affects the process of written self-expression.

Some respondents say that as the years pass, the cancer experience has lost its primary significance, while others say that the individual memories connected with cancer will never fade. The following examples, from the co-letters, mediate adequately the lack of individual awareness of emotionally challenging, lived situations (where 'awareness' is defined as the ability to notice and understand). In addition, they show the continuous adaptation of personal awareness of the past in an ongoing, changing, situation:

*Elämän tarinat ja niissä eletyt kokemukset alkavat aina jostakin tunteesta kasvaen ja muuttuen koko ajan toiseen muotoon ja toiseen tunteeseen käyden läpi varmaankin psykologisia lainalaisuuksia, jotka on helppo tunnistaa ja nähdä jälkikäteen, mutta jotka itse elettyinä hetkinä ovat niin voimakkaita ja ajassa kiinni olevia, että on täysi mahdottomuus käsittää edes niiden olemassaoloa: niinpä rakkautta seuraa usein kyllästyminen, sitten inho, välinpitämättömyys ja lopulta ehkä unohduksen armo. Joskus tunteet myös päättyvät jonnekin ikään kuin "tunteiden hautausmaalle" tehtyään täyden matkansa ja antavat samalla meille varmuuden kokemuksesta seuraavaa, ehkäpä samantapaista tunnetta varten. Ne ovat myös kuin sirpaleita, jotka muodostavat elämän saviruukun: erikseen palaset voivat viehättää muodollaan tai värillään hetken, mutta vain yhdessä ne kokoavat saviruukun; niillä on siis tarkoitus, olkoonkin että ne saattavat olla hyvinkin mitättömiä. Tämä tarina kertoo sellaisista tunteista, jotka eivät vielä ole päättäneet kiertokulkuansa.*

Lifestories and the experiences lived in them always begin to grow out from some sort of feelings, and change their form all the time to other feeling, possibly going through some laws of psychology that are easy to recognise and see afterwards; but during the lived moments they are so powerful and fixed by time that it is impossible to understand even their existence. Indeed, falling in love often continues with being fed up, hatred, ignorance and later perhaps the mercy of forgetting. Sometimes feelings also end up somewhere like 'the graveyard of feelings' after making a full turn and giving us the

confidence for forthcoming experience, and perhaps for similar feelings. These are also like bits and pieces that form a clay bowl: they have meaning, although this may be quite insignificant. This story tells of such feelings that have not yet ended their circular journey. (401)

*Päiväkirjasta: "Minulta meni muisti. Unohtui, missä on osaston wc, miten mennään laboratorioon. Kädet tärisivät lakkaamatta, katse tuijottaa. En voi edes sanoa, että kuolen tähän tuskaan." Päiväkirjamerkinnot tästä eteenpäin ovat hajanaisia, lyhyitä. Niitä on vähän. Valokuvia osastolta on jonkun verran ja Heidillä kirjeitä osastolla tutuksi tulleilta ystäviltä. Dokumentteja on perin vähän. Silti sen kaiken muistaa. Tuska palaa uudelleen sydämeen, kun siitä puhuu tai ajattelee.*

From my diary: "I lost my memory. I forgot where the toilet is, and how one goes to the lavatory. My hands were shaking constantly. I stare. I can't even tell if I will die from this suffering." The notes in my diary from this moment on are severe, short. There are few of them. There are some pictures from the department and H. has some letters from those she learned to know there. There are few documents available. However, everything stays in the mind. The sorrow returns to my heart, as I talk or think about it. (406)

Regarding cancer narratives, it is significant that our memory makes possible time travel through events connected by subjective time and space. This, however, is connected with the particular person and his or her individual autonoetic (looking at the world) awareness in the past. This awareness of the past, in the past, enables a person to recall it in the present, which in the context of the writing competition, enables conscious recollection of past events. Such recollection creates time travel from the present to the past, allowing one to re-experience one's own previous experiences (Tulving 2002, 6). Through the given reasoning, I wish to point out that this kind of selectiveness based on individual ability to memorise, remember and recollect, strongly affects the writing process. The recollection of individual memories has little to do with listing the lived events. This is merely an active process in which events from the past evoke strong emotions and new thoughts. For individuals, such recollection may be challenging, although psychologically beneficial. For the study of materials representing the process of such recollection, this means the events and themes described in cancer narratives have, again, lost some of their accuracy when connected to reality, whereas in the context of cancer experience the kind of 'forgetting' that may be interpreted as intentional also becomes important.

## **Detecting ‘meaningful silence’**

When analysing cancer narratives it is also necessary to analyse the limitations set on composing a written narrative. In Finland, as in many other societies, it is uncommon to share intimate or revealing topics with others (Linde 1993, 47–48). Discussing illness is a culturally stigmatised act, similar to discussing such topics as loneliness, poverty, loss of work and ageing (Varis 1998, 177). The narratives under examination point out a very important social aspect of cancer: in many ways the illness stigmatises its carrier. Consequently, people do not know how they should act, and whether they are ‘allowed’ to discuss their illness publicly. If they choose to talk about it openly, they risk loss of social position, respect of friends, and contacts with acquaintances. According to the writing analysed, such societal misjudgements are unfortunately not uncommon among Finns (see Chapter 5). For that reason, many cancer patients intending to avoid these inconvenient situations, and possible misjudgements, decide to be silent and ignore the topic in everyday conversation.

I have argued that since discussing cancer-related problems openly is experienced as objectionable, cancer patients may see writing as a liberating opportunity to express their inner concerns (Hawkins 1999, 35). The problem is also that through writing, which is mediating individual experience and social and cultural attitudes and beliefs, people have to reveal themselves. This means that they have to decide how to write about significant aspects of their illness in order to avoid possible criticism and other negative reactions. In this sense, it is interesting that people write about socially and culturally significant themes. Furthermore, it is interesting to see how language and culture affect written self-expression when the writer discusses issues that are defined as marginal in everyday communication.

Ethnographic studies of language use have shown that methods of language use are not universal. The ideologies captured in language are part of cultural conceptions that are adopted during the enculturation process characteristic to a particular speech community (Och and Schieffelin 1984, 276–278). In every speech community there are certain ideas interpreted as marginal in everyday communication. Every person dealing with marginal issues is aware of them. Illness, death, suicide, sexuality, birth, bodily concerns; in addition poverty, politics, race, punishment and crimes may need careful choice of words. Members of a speech community are thought to behave according to the norms of a particular culture. These norms including avoiding undesired words and issues, both in order not to

illicit unwelcome reactions, and also to avoid influencing the culturally determined order in a way that would be perceived as negative. In this way, the enculturation process sets (institutionalised) frameworks around different discourses significant in human communication.

The deliberateness of this phenomenon, guiding as it does the use of language, is an interesting issue. On an individual level, uncomfortable feelings are deeply connected to the feeling of shame and fear. The feeling of shame could be approached as the most dynamically restricted and controlled feeling in culture (Ronkainen 1999, 135). Although the feeling of shame is not in direct correlation with culturally agreed taboos, shameful issues are communicated carefully, or stay entirely unmentioned. This means that certain words, themes and issues gain the position of ‘non-observable’ aspects of language use, and accordingly set limitations on written self-expression. The awareness of such limitations creates an interesting situation in which the context or discourse itself is non-observable, while the consequences remain evident (van Dijk 2006, 164).

Based on the cancer narratives, it is only possible to guess the extent to which cancer patients’ experiences are covered by the ‘meaningful silence’ set by the ideologies mediated by language. Fortunately, when observing the numerous textual accounts, it is possible to recognise words, episodes and themes that appear to be marginal, or are somewhat complicated to tackle. Our understanding of the limitations that cover cancer communication helps us understand the reasons why talking about cancer is difficult in everyday communication. Equally, it helps us to comprehend why writing about personal cancer experiences has been both experienced and described by respondents as an extremely beneficial, even liberating process. Consequently, despite the culturally bound, and language-based, limitations set on cancer-related discussion, the opportunity to express oneself and to mediate the consequences of being diagnosed with, and having, cancer on individual, social and societal levels has resulted in a collection of texts that reflect human minds and reasoning, forming a remarkable ethnographic context within which to study the meaning of cancer.

## **The personal voice and culturally bound representations**

Writing a story is not only about listing events. Writing a story is so much more. Writing, as with all other methods of self expression, is a communicative act full of meaning. In the

search for better communication, people form their individual stories in accordance with traditional or national norms of written utterance (Bakhtin 1986, 65). This means that writers do not share all of the inner concerns that might have affected them during their illness period. When writing, they activate their episodic memory and recall past events and episodes that evoke strong feelings and new ideas. When composing their stories, the recalled events and episodes become interpreted, and will be altered according to the social norms and rules that govern the production of a fixed narrative.

The writer must carefully consider the rules of performance (written self-expression), soci(et)al expectations (readers) and the general social and cultural context (discourse). Although people follow individual narrative patterns, depending on how they have been affected by their personal experience, the written narrative becomes evaluated through the cultural understanding of successful writing (communication). This leads to writers making choices on structural, vocabulary and expressional levels, and therefore people construct their narratives based on their own writing skills, which are themselves constantly being compared with the individual's image of 'proper' written narrative:

*Tässä tämä sotkuinen sepustukseni, lähetän tämän kuitenkin kun ette täydellistä vaatineetkaan. Tämän kirjoitti vanha ihminen 1920 syntynyt, vanhalla koneella ja yhdellä sormella. Oletteko hyviä ja korjaatte kirjoitus ja ajatus virheet ja poistakaa tarpeettomat.*

Here comes my messy letter. I will send this, as you did not ask for perfect writing. An old person, born in 1920, has written these texts with an old typewriter and with one finger. Please, be so kind as to correct my writing and thinking faults and remove parts that are unnecessary. (023)

As every cancer experience is to some extent unique, cancer narratives concentrate on important themes and issues that are personally significant for the respondent. On the other hand, because of the culturally pre-set rules that guide the process of written self-expression, people select themes and issues for discussions that might also be significant for others, particularly the addressee reading cancer narratives. This, again, means that themes that are selected for writing, and which are thus often repeated, have a particular significance in the context of cancer experience in the ethnographic sense.

When the Danish folklorist Bengt Holbek proposed his idea in connection with the interpretation of fairytales (Holbek 1987) it caused a revolution in folk narrative research. Human scientists, among them folklorists, asked countless questions about the connections between folk tales and reality. Holbek's colleague Michèle Simonsen's criticism of those

interpretations points out a very important aspect of narrative research: “All those scholars seem to forget that a tale is also a work of art, which partly follows its own laws, and that the relationship between reality and fiction is not a direct reflection, but a complex process of transformations” (Simonsen 1993, 124). Simonsen points out a significant aspect that often stays unnoticed in studies adopting the modern narrative approach. Although the participants intend to make their narratives as ‘accurate’ as possible, accuracy is impossible because of the inner rules of composing a narrative, as well as the individual, linguistic and cultural limitations that govern narratives. Accordingly, some writers clearly make use of their written self-expression skills and compose truly enjoyable plots full of drama, comedy and masterful confrontations. Other texts are impulsive and confusing, even though the writer’s main ideas and aims are still graspable.

Folklorists and other narrative researchers have persistently pointed out that composing a narrative is not based simply on individual knowledge and experience but is framed and modified by cultural and socio-historical discourse. Dell Hymes has called it a personal voice (Hymes 1985, 391), and says that by choosing, we communicate something personal as well as cultural, if we have the skills to recognise it. In his important work *The Dialogic Imagination* Mikhail Bakhtin has defined the diversity and stratification of voices in written texts as heteroglossia (Bakhtin 1981, 263). According to Bakhtin, the value-laden way of self-expression may be described as a permanent dialogism fulfilled with intentional (intended) words. Therefore, written cancer narratives must be viewed as personal experience narratives, but also as intended social speech acts targeted to the organisers of writing competition, cancer patients, medical practitioners, other decision makers, etc., with a particular goal.

## **The status of written cancer narratives**

An important problem when analysing written cancer narratives is that of the status of the text. Namely, what factors ‘fix’ the text so that the intended meaning may be interpreted? In his study on text and textuality, William Hanks (1989) has pointed out that the status of text consists of at least five significant parts: the boundaries of texts, the “centring” of text within some interpretative matrix, text as a performance, the reception of the text, and the construction of synchronicity (Hanks 1989, 103–113). Here, concerning the status of cancer narratives, I observe the first three of the five parts suggested by Hanks. The



construction of textual synchronicity depends on social histories, which I have already considered above; and to the fourth part, regarding the reception of the text, I will come at the end of this chapter. The first three parts, however, are useful notions with which to point out the importance of schematic aspects governing the attempts to gain the ‘intended’ meanings appearing in the texts.

The narrative schema proposed first by William Labov and Joshua Waletzky (1967), and later in more detail by Labov alone (1972), has been one of the central theoretical approaches influencing the folklorist and other narrative researchers, while also drawing the folklorist’s attention to structural segments (episodes) such as abstract, orientation, complicating action, evaluation, and coda in personal experience narratives and other folklore genres. The Finnish folklorist Annikki Kaivola-Bregenhøj has said of the adoption of Labov’s schema, resulting in a folkloristic narrative analysis understanding, that, “the schemes or conventions of specific genres do not guide the production of pure traditional narratives but narrative in general” (Kaivola-Bregenhøj 1996, 36). The schematic analysis of narratives points out two important aspects, first, that a narrative is a series of episodes (the details vary from one researcher to another), (Kaivola-Bregenhøj 1996, 34–36; Siikala 1990, 38–40; van Dijk 1980, 113–115; Chafe 1979, 26; Kintsch 1977, 38; Rumelhart 1975, 222), and, secondly, that different genres have their own (traditional) criteria and limitations governing their content and performance (Siikala & Siikala 2005, 133). As I have pointed out above, this is an important concept when considering the analysis of thematic narratives and the understanding of their significance as ethnographic sources.

The first part of the status criteria stated by Hanks is certainly most important to textual analysis as it endeavours to define the borders of the object under study. According to Hanks, the boundaries of a text can be defined, along with its difference from non-text. In that case, the borders of the selected texts are best defined by the text’s narrative nature. Namely that creation of a narrative also creates the difference between text describing events (narration) and the lived events (experience) themselves. Even if I have discussed a certain incompleteness among the cancer narratives, we could suppose that texts are never finished (Ingarden 1973, 251), and thus, the ‘fixed’ form of the written text gives the selected narratives their finished status. Putting focus on the schematic status of textual works forces, according to Hanks, a rethink of the idea that boundaries between what belongs to a text, and what does not, are fixed. Hanks emphasises that textual boundaries may be dialectically constituted in the interplay between schematic and concretised moments, including the ‘black spots’ in the schema. These represent “the spaces between

portions of a broken line” that constantly remind researchers “to connect the dots and fill in the meaning” that one needs in order to interpret (Hanks 1989, 105). In the schematic sense, the cancer narratives’ boundaries are indeterminate, with the main reason for that laying in intertextual and extratextual factors that are responsible for the multitude of voices present in every text. In order to understand the ‘voicing’ in any particular text (Hanks 1989, 114), it is necessary to be aware of aspects that influence the respondent’s intended meanings within a text.

The second part proposed in Hanks’ work, the ‘centring’ of text within some interpretative matrix, raises an equally interesting question about the status of the materials under study here. The individual cancer experience is determined by temporal and spatial factors within a certain context, as mediated by the written texts. To understand this we must be aware of the context as defined by the dialogism between socio-historical development and sociocultural discourse. When the context that contextualises the text (narrative) becomes defined, it is easier to concentrate on analysing episodes that mediate significant events and activities. Accordingly, Hanks has suggested that “these structures have in common that they are relatively fixed configurations of information corresponding to actionable wholes (such as types of events, activities), global scenes, sequential routines, and other extended domains of reference” (Hanks 1989, 110). Thus, here again, the schematic structure and its compositional parts leads towards the understanding of the meanings fixed in text.

The fact that the thematic writing studied here was written at the request of the folklore archive is also a significant factor relating to centring in thematic narratives. Therefore, it is interesting to examine how the context of the writing competition influenced the final texts. This influence has been analysed in Ulla-Maija Peltonen’s (1996) work *Punakapinan muistot* (Memories of the Civil War) and in Pauliina Latvala’s (2005) book *Katse menneisyyteen* (A Glimpse Into the Past). Pauliina Latvala has suggested that the Folklore Archive at the Finnish Literary Society has a traditional role as a ‘paternal’ institution that gathers oral history and the individual experiences of Finns. Latvala points out that, although respondents may have very different understandings of how a proper response to a folklore archive should be composed, the idea of composing a text for archive has a certain impact on a respondent’s identity (Latvala 2005, 34–35). Foremost among these, the context of the writing competition influences the ideologies of the texts composed. In the case of the cancer narrative, this ideology is influenced by the sociocultural and medical context, detectable in the ways in which people comment on sociocultural

attitudes towards cancer patients and patient-doctor communication in healthcare institutions.

From the point of view of self-expression, interpreted here as the intended social speech act, the status of cancer narrative is on the whole very important. In addition to the psychological and constructive value (inner negotiation) fixed in the writing process, the importance of cancer narratives comes from their status as an ethnographic source sharing sociocultural attitudes and ideas about cancer. Compared to the ethnomedical sources used in this work, authorial speech in cancer narratives adds to the written archive sources a multitude of voices important in comprehending the central question of this work: What is going on?

## **Cancer narrative as a thematic whole**

John Dorst has written that, “no genre exists outside of the dense thickets of citation, commentary, resistance approval, mimicry, parody, etc., that constitute the responses of other points of view”. He continues with Dell Hymes’ idea that generic interactions are ongoing accomplishments, often variable or uncertain in outcome; for the most part they involve the subconscious genres of everyday discourse (Dorst 1983, 414; Hymes 1975, 351–352). Dorst’s suggestion builds on Bakhtin’s idea that secondary speech genres (mainly written) absorb various primary (simple) genres during their formation or generation (Bakhtin 1986, 61).

Cancer patients’ writing includes numerous conventional discourse genres or primary genres that are particularly attractive for folklorists. Within the secondary narratives are proverbs, sayings, predictions, dreams, jokes, and various beliefs concerning cancer that carry many significant cultural values. From the ethnomedical point of view cancer narratives describe popular beliefs about the origin of cancer, the problems with defining the illness, and the complexity of prevention techniques. Furthermore, cancer patients’ writing communicates the sociocultural expectations confronting cancer patients, problems with patient-doctor relationships, and the challenges faced in the attempt to adopt the practices of self-help. Equally meaningful are references and citations from various books, calendars and diaries, as well the biblical quotations that have gained significance during the individual’s illness course; likewise the wide range of poems written by cancer patients expressing their deepest feelings are also tempting for folkloristic enquiry. All these simple

genres invite immediate folkloristic investigation, although Bakhtin's warning finger points at us. He points out that the difference between primary and secondary (ideological) genres is very great, and indeed fundamental, although this is precisely why the nature of the utterance should be revealed and defined through analysis of both types (Bakhtin 1986, 62).

According to Bakhtin's interpretation, a one sided orientation toward primary genres inevitably leads to vulgarisation of the entire problem. The very interrelations between primary and secondary genres and the process of historical formation of the latter sheds light on the nature of utterance (and above all on the complex problem of the interrelations between language, ideology and worldview). In his article about discourse genres in theory and practice, William Hanks examined genres as a part of conventional discourse. He claims that the use of genres is foremost dependent on one's linguistic and communicative *habitus* (Hanks 1989, 112–113; Hanks 1987, 670, 687–688). As with genre and cultural convention, the ability to recognise discourse genres lies mainly with the reader or addressee (Hanks 1987, 682; Bakhtin 1986, 95–96). Where the frameworks of cultural understanding are set correctly, the reader acknowledges the emergence and the concept of genre. Therefore, it is very important that cancer narratives as thematic units become interpreted and analysed as a whole, meaning that when approaching cancer narratives it is important to be aware of numerous internal and external aspects regarding these narratives. To understand written cancer narratives one has to be aware of the textual qualities, the writer's intentions regarding the use of different genres, collecting aims and circumstances, the socio-historical and cultural frameworks of the particular discourse. Furthermore, one has to be aware of the consequences linked to the topic in order to recognise if something 'non-observable' is uttered as well.

## Conclusions

Narrative is a communicative tool and thus the composition of narrative is constantly influenced by sociocultural surroundings and norms, as well as individual reasoning, utterance skills and the ability to remember and recall individual events. Thus, it is important to remember that narratives do not exist *per se*. Narrative is an act of self-expression that represents the lived experience containing intended and thus meaningful acts. Accordingly, narrative events become selected by the narrator and placed in an

optional spatial and temporal dimension. The respondent chooses the characters and paints the necessary oppositions to make the desired point. Considering this, the cancer narratives analysed here are fictive representations linked with some aspects of reality. Theoretically, all the events, thoughts and emotions described in cancer narratives belong to the narrative world.

Despite their fictive character, cancer narratives form an excellent ethnographic source that allows the examination of the personal, societal and sociocultural meanings of cancer. Like all personal experience narratives, cancer narratives mediate the individual's inner thoughts and everyday communication, as well as socioculturally agreed expectations. Thus, cancer narratives may be approached as representations of cancer patients' inner negotiation, influenced and framed by everyday action and socioculturally agreed expectation.

When dealing with narratives, one should always have in mind that any narrative that becomes verbalised and expressed, is an interpretation that becomes influenced by the cultural expectations set on the communicative act and the particular discourse. Furthermore, the writing process, in a similar way to storytelling, consists of small individual choices. The writer chooses what is worth sharing and what is insignificant. In this context, I want to emphasise that the benefits of written text, as opposed to oral performance, lay in the writer's opportunity to consider his or her self-expression carefully and, based on individual linguistic and communicative *habitus*, present narratives in their 'fixed' form in a particular situation. Foremost, the act of self-expression is a conscious process and thus the generated narratives may be analysed as fictive, or 'near' to individual experience. This holds true even if, in reality, the individual interpretations of one's feelings, experiences and thoughts lose their meaning as time passes. Because of continuous changes in situations that affects human life, previous interpretations become overlooked and, in the case of persisting individual value, re-interpreted.

Before moving further, I emphasise that narrative-based study cannot concentrate only on narrative content. Above all, any scholar dealing with thematic narratives should consider the interrelation of primary and secondary genres in order to understand a respondent's intentions and the significance of the given representations under study. More importantly, one should be aware of the ethnographic context of a particular situation, while the sociocultural setting or discourse captured in thematic writing is far more stable than individual interpretation based on lived experience.

### **3 Cancer in Finnish Folk Medicine**

Pathography is an immensely rich reservoir of the metaphors and models that surround illness in contemporary culture. Accordingly, these written interpretations of illness experience must be understood as constructs, revisions, and in some cases, creative distortions that expose a variety of ideological and mythic attitudes about illness today (Hawkins 1999, 25). In this context, I wish to point out the significance of understanding language as a tool that mediates culture-bound understandings, especially through changing times and situations. Language and traditions outline the cultural setting for human reasoning by offering schematic structures and linguistically mediated rules with which to understand and process the surrounding social and cultural setting. Accordingly, culturally agreed knowledge and understanding affects the way people form ideas, although their interpretations are based on individual reasoning and experience (Hacking 2009, 77–79).

The American anthropologist Kathryn Woolard has closely examined theories on language ideologies in different cultural contexts. In her writing she has proposed that “cultural frames” have social histories (Woolard 1998, 10). This suggestion reminds us that in addition to culturally characteristic ideas, language, and accordingly also culture-bound traditions, capture the development of the social structures that form particular discourses affecting human minds. This means when coming to an understanding of the popular discourse on cancer, it is important to compare socio-historical processes and culturally accepted communication, and to detect the frameworks of culture-bound reasoning.

This chapter is an attempt to create historical context in order to understand better the patients’ argumentation analysed in this work. To recall and reconstruct tradition-bound images of cancer from the past, I shall use materials available at the Folklore Archive of the Finnish Literary Society, kept in various collections since the second half of the 19<sup>th</sup> century. It seems reasonable to use this rich source of material as it allows the introduction of unique, and so far unstudied, folk medical ideas relating to cancer, its occurrence and folk medical treatments. This analysis also demonstrates that cancer is by no means a new health concern in the Finnish context.

The archive materials reveal the period before the socially supported healthcare system gained its dominant place in Finnish society. In Finland new legislation on citizens’ rights for health and public healthcare was proposed in the 1920s (Helén & Jauho 2003, 25).

From this period onwards attempts were made to introduce a socially supported and controlled medical system to the Finnish people. This also meant suppressing the traditional folk medicine practised among Finns. Despite these efforts folk medical practices lasted until the 1960s for political and economic reasons (Naakka-Korhonen 2008, 187–189; Naakka-Korhonen 1997, 108–109; Piela 2006, 298–299). Since then suffering Finns have received help with their health concerns from socially supported healthcare centres and centralised hospitals, where the treatments given follow the newest discoveries of biomedicine. The final change in the healthcare system took place in the middle of the 20<sup>th</sup> century, removing mainstream Finns from their traditional healing methods, so that today many people in Finland only have faith in biomedical cures (see Chapter 8). However, according to previously culturally set frameworks, their health beliefs are still bound up with the folk medical past. In this chapter I shall describe various factors relating to cancer before the widespread acceptance of biomedical healthcare treatments in Finland. This is an attempt to demonstrate that several popular ideas relating to cancer still resemble these beliefs, and also to show the fears deriving from historic discourse.

Although ethnomedical records are indeed valuable when examining such argumentation, it must also be said that the available material is by no means an easy source when making a coherent study, at least when it comes to presenting certain numbers or statistics. Despite the inherent difficulties, if we agree that culturally accepted attitudes derive from the historical development of the human environment, then the available ethnomedical records offer a good opportunity to recall tradition-bound ideas about cancer that, via language, influence human reasoning today and thus become embedded in cancer patients' writing. In my opinion, this kind of diachronic insight makes some current concerns in popular cancer discourse clearer and helps to explain some general ideas about the mythical nature of cancer in a more detailed manner.

## **The problem of recognising cancer among archive sources**

The materials available in the Folklore Archive have little to do with the rational cancer explanations characteristic to modern medicine. Although the end of the 19<sup>th</sup> century and the beginning of the 20<sup>th</sup> century marks a period of great discovery and continuous change for medical discipline, in everyday life this change was less apparent as there were too few

educated doctors to meet the needs of thousands of patients. In addition, within the medical discipline as a whole, this movement towards rational reasoning did not take place as quickly. Nevertheless, during the second half of 19<sup>th</sup> century the new generation of Finnish physicians slowly stopped believing that illnesses were independent beings (Pesonen 1990, 31), which made their attitudes somewhat different from those of ordinary people.

In today's medicine, the early detection of cancer is the dominant imperative for future treatments. A century ago the diagnosing procedure, both in scientific and folk medicine, was still mainly manual or visual, and explanations regarding illness origin, which influenced the selected treatments, mainly based on a combination of traditional belief and personal experience. Indeed, the possibilities for illness diagnosis became much better when the microscope was introduced and pathological study become routine. The diagnostic tools that made it possible to examine the body from inside were implemented for medical use at the end of the 19<sup>th</sup> century (Porter 1999, 575). Finnish physicians, however, were unable to serve their patients as expected. The lack of educated doctors was so great that, for example, in the 1860s a county doctor had 20 000 patients to take care of (the number had been twice as high 20 years earlier) (Naakka-Korhonen 1997, 108). Thus, there was also a continuous lack in terms of offering the best possible cure for numerous sufferers. This means that people were used to taking care of themselves, with the doctor's help sought in only the most complicated cases.

The main problem was that although the number of doctors and other medical personnel was constantly rising and small hospitals and clinics were established, ordinary people did not trust the ideas and methods that trained doctors introduced and practised. The doctor had a different social status and his way of dealing with illnesses was treated with great suspicion (Naakka-Korhonen 1997, 107). Among ordinary people, first aid originated from the domestic sphere and often-local healers, who represented the views and beliefs of local people, were consulted in cases where domestic healing practices were not successful.

The lack of competence when it came to telling the difference between illnesses was a common problem of the time. In his book about patient-doctor-patient relationships among the Finnish peasantry between 1889–1916, Finnish historian Anssi Halmesvirta has proposed that the peasantry did not recognise the symptoms of most common illnesses, which meant that when health problems occurred, people waited until the symptoms became “recognisable” (Halmesvirta 1998, 44). According to archive material, in the case of cancer this meant that the disease was first recognised only when it was visible as an open wound, or manually detectable as some kind of external growth. For these reasons it



is also difficult to decide which illness is described and handled in the Folklore Archive texts.

Among the studied ethnomedical records, I found only one text advising how to diagnose cancer in the domestic context. However, I believe the following method was more common than the available archive texts would suggest:

*Jos epäilee että itsessä on syöpähaava, saa siitä seuraavalla tavalla tiedon: Otetaan onkimato ja pidetään sitä haavan päällä sormien välissä. Jos haavassa on syöpä, kuolee onkimato pian. Jos onkimato ei kuole ei ole myöskään syöpää.*

If you think that you have an eater wound you will find it out in the following manner: You take an earthworm and keep it on the wound between your fingers. If the wound has eater in it the earthworm will die soon. If the earthworm does not die there is no eater.

SKS KRA Viljakkala, Mattila Martti E. 3809. 1936 < Jeremia Hieturi, 82 y.

Initially, in the folklore archive I examined the available ethnomedical texts dealing with phenomena called the eater (*syöpä-kortisto*) and the growth (*kasvannainen-kortisto*). It soon became clear that using only the illness ethnonyms was ineffective in distinguishing between different cancer types, and between cancer and other health problems of the times. To gain a better picture I would have had to go through all the available materials on ethnomedicine (*kansanlääkintäkortisto*), which would have been very time consuming and also unproductive in relation to the main aims of this thesis. As an alternative, I chose to go through a few selected ethnomedical collections.

The first ethnomedical collection I selected for closer examination was the Finnish Physicians Association (*Suomalaisen lääkäriseuran*) *Duodecim* materials collected in 1907 by Ilmari Laitinen and Veikko Puntala. Studying these materials confirmed that the decision to concentrate on certain collections was beneficial as it gave a far better overview of the (folk) illnesses characteristic of the time (the late 19<sup>th</sup> and early 20<sup>th</sup> centuries). Based on this first collection, I gained the impression that various cancer(s) had had a rather unimportant role in Finnish folk medicine and were also rather badly identified. Based on 22 intuitively selected texts concerning cancer, it seemed that the disease could have been anything from *säärihaavat* ('badly cured wounds on feet') (SKS KRA E 190 5 *Duodecim* 328. 1950) to *watsanpoltteet* ('stomach pains') (SKS KRA E 190 5 *Duodecim* 367. 1950 < Simo Juho Sirkka < Kittilä).

In 1948 *Kalajokilaakso*, a local newspaper in the west of Finland, organised a competition to gather accounts relating to folk medicine. Among the materials contributed

by Pentti Heilala I found four accounts that could (possibly) describe the treatment of carcinogenic illnesses in folk medicine. These were texts that describing healing *syöpä* (the eater) (SKS KRA E 183, 13 (10) < Ylivieska, Lahdenperä 1948 – Heilala, Pentti < Ida Kangas), *koin tukko* (closed moth) (SKS KRA E 183, 18 (15) < Oulainen, Piipsjärvi 1948 – Heilala, Pentti < Elvi Nasila), *munuais- ja rakkotauti* (kidney and bladder illnesses) (SKS KRA E 183, 22 (19) < Haapavesi, Vatjusjärvi 1948 – Heilala, Pentti < Emmi Pirttimaa) and *struuma* (goiter) (SKS KRA E 183, 55 (45) < Alavieska, Taluskylä 1948 – Heilala, Pentti < L. K. Vierimaa “Lieppastiina”). Again, the decision that these texts possibly deal with different cancers was based on the researcher’s intuition by combining illness descriptions and selected treatments, without confirmation.

Additionally, I examined the materials collected in 1964 from the folk medicine collection *Medica* to see the (possibly) changing importance of cancer, as well as the folk medicine collection organised in 1978. For example, among the answers received in 1978 I found twelve descriptions of how to heal cancer, or how to strengthen oneself when suffering from it. Materials representing the times after the advent of biomedical health care indicate an important change in societal life, including the use of folk medical practices. In most cases cancer, like other illnesses of the time, was no longer diagnosed and treated at home but in state supported hospitals. Thus, one may suggest that from approximately the 1960s onwards, treatments deriving from folk medicine are understood by most Finnish citizens as alternative or complementary cures, rather than as primary cures (Naakka-Korhonen 1997, 108–109; Piela 2006, 298–299).

## Cancer’s ethnonyms

Despite the fact that cancer, like many other diseases and illnesses, was not well recognised among ordinary people, it has received many vernacular names. People refer to cancer with words such as *vieras* (the stranger) (SKS KRA Sääksmäki. Tuomarila, Kalle. VK 102: 113. 1912), *ruumiin mato* (the body worm) (SKS KRA Viitasaari. Albert Rautiainen 2768. 1953 < Emil Hämäläinen, b. 1896), *ruumin koi* (the body moth) (SKS KRA Sortavala, Otoisten kylä, Hyvärinen, Juho KRK 141: 482. 1936 < Maija Hyvärinen b. 1905). The most popular names, however, are *syöpä* (the eater) or *syöpäpahka* (the eater bump) (SKS KRA Sortavala, Laine Elli KRK 144: 336. 1935 < Sofia Savolainen, 78 y.), *kasvannainen* (SKS KRA Saarjärvi. Harju, Otto. 433. 1938 < Aukusti Kyyrä, b. 1867),

*kasvain* or *kasvi* (the growth) (SKS KRA Rääkkylä Hirvonen, Iida KRK 156: 35. 1936 < J. Harinen, 60 y.) and *rupi* (the scab) (SKS KRA Viitasaari. Harju, Otto 2008. 1938 < Ville Kauppiainen, b. 1864). The word *rupi*, rather common in ethnomedicine, is only used once in the cancer narratives under study here: *Minulla oli käsivarressa sellainen musta rupi, en pitänyt sitä vaarallisena. Se sai olla siinä jotain 8 eli 9 kuukautta.* “I had such a black scab on my arm, I did not think it was dangerous” (144).

In the ethnomedical records, the noun ‘eater’ is used to refer to patients’ internal problems, the ‘growth’, to their external conditions. Sometimes instead of *syöpä* the words *refta* or *krefta* are used, which derive from the Swedish *kräfta*, also used by medical doctors at the time:

*Rehta on se kun ruumiista kuluu pois liha ja nahka, eikä sitä voi millään parantaa. Sinikiviä ja pikiöljyä siihen koetetaan panna, mutta ei se auta.*

Cancer is when the body loses flesh and skin and there is no way to heal it. They try to put the blue stone and tar oil [*Pyroleum picis*] on it, but it does not help.

SKS KRA Sodankylä, Samuli Paulaharju 20478. 1932 < Kurtin Eeva, 70 y. Mp. 1920.

Ethnonyms like *paisuma* (SKS KRA Kortesjärvi M. Nurmio 950. 1888 < M. Filipakka, 60 y.) *bajari* (SKS KRA KRK 145: 7 Salmi, Vihtilä. Mikkonen, Mikko. 1935 < Akuliina Laasarof, 49 y.), *rusto* (SKS KRA Lapua. Hautamäki, O. K. 300. 1935 < Anna Huhta, 66 y.), *pahkura* (SKS KRA Juva, Näärinki. Kolari, A. Elisabeth KRK 79: 4. 1936 < Sirkku Ylönen, ompelija 25 y.), *gruumi* (SKS KRA Sulkava, Rahkola. Karppinen, Juhani KRK 78: 158. 1935 < Alb. Karppien 82 y.) and numerous other local names are only sometimes used to describe cancers. Typically the same words are used to refer to several other problems, such as boils, abscesses, warts, infections, gangrene, allergic reactions or various skin problems caused by bad hygiene and *syöpäläiset* (parasites) (Naakka-Korhonen 2008, 189–191). For example, the notions *pääsyöpä* (the ‘head eater’) or *rupi päässä* (‘scab in the head’) (SKS KRA Kärsämäki, Keränen Erkki 42+43. 1883) do not signify brain cancer but parasites in the scalp resulting in hair loss and skin problems.

According to the available materials, the concept of *ihosyöpä* (skin cancer, lit: ‘skin eater’) was the most commonly recognised cancer type (SKS KRA Lappajärvi < Heikki Toivonen, E 193: p. 239. 1950; SKS KRA Ritola, Jaakko. VK 81: 10. 1909 < Antti Hintta), although, as already mentioned, it was also used to refer to other skin concerns that normally had nothing to do with skin cancer (Rytönen 1937, 214–215). For example, the ‘skin cancer’ affecting young children, also acknowledged in official death records (in

Swedish *likmask*, *barnkräfta*), in fact referred to an infection called noma or *cancrum oris* (Vuorinen 2002, 219). As the options for making laboratory tests were limited, there was no way to find out that noma was caused by bacteria.

The word *nenäsyöpä* (lit: ‘nose eater’) also occurs in the studied materials (SKS KRA Laihia. Salokannel, Tyyne KRK 199: 1430 < Potinmomma). In current medical terms it may be explained as a problem connected with undiagnosed syphilis, a very common health problem that was misunderstood for a long time, and therefore because of the lack of necessary knowledge and facilities, one that remained untreated (Halmesvirta 1998, 209–218). On the other hand the expressions *rupi nenässä* (‘scab on the nose’) could be interpreted as some kind of external growth similar to warts (SKS KRA Inari. Samuli Paulaharju 8157. 1930 < Eeva Nuorgam, 32 y.).

Other cancer types typical in the Finnish context (Koskenvuo 1994, 43), such as gastric carcinomas or lung cancer, occurred under names like *vatsatauti* (‘stomach illness’) (SKS KRA E 190 5 Duodecim 458. 1950 < Aate Härkönen < Rovaniemi), *keuhkotauti* (‘lung illness’) (SKS KRA E 190 5 Duodecim 325. 1950); again these ethnonyms also refer to completely different medical problems in the digestive system, such as tapeworm (Naakka–Korhonen 1997, 141) or in the case of lung ailments, tuberculosis, another very serious health problem of the time (Kuusi 2003, 33) that caused *tuberkeli pahka* (‘tuberculosis bump’).

It is not unusual, when describing cancer, for people to use different onomatopoeic expressions, such as *kolotus* (SKS KRA Suomussalmi. A.R. Tuomas-Kettunen 236. 1938 < Kaija Seppänen, 55 y.) and *porotus* (SKS KRA Laihia. Brandt, Herman. 1156. 1891 < Fredrika Jäärnberg), referring to certain kinds of pain in different body parts.

Perhaps the best recognised and acknowledged cancer type of the time, in addition to skin cancer(s), both in folk medicine and scientific medicine, was breast cancer. Despite nonexistent methods of anaesthesia, breast cancer surgeries took place as far back as Antiquity. The most famous breast cancer surgeons during the Middle Ages were Paulus Aegineta (625 – 690) and Guy de Chauliac (1298 – 1368) from France (Forsius 2003). According to cancer patients’ narratives, in the 1950s similar painful surgeries, causing inconceivable suffering to patients (246), still took place in Finnish healthcare centres at that time.

In the developing medical discourse, breast cancer was interpreted as a problem for elderly women that occurred during the menopause (Vuorinen 2002, 219). The medical discourse of the time encouraged woman to observe and examine their breasts from time to

time; and in case of anything suspicious to go to a doctor promptly. The scientific descriptions of breast cancer caused insecurity and fear, mainly because people did not know how cancer spread – was it an infection or an inherited illness? As is still true today, doctors could not answer this question, which certainly did not make patients' situations any easier (Halmesvirta 2002, 95). In the ethnomedical records, breast cancer is mainly referred to as *rintahaava* ('breast wound') or *syöpä rinnoossa* ('eater in the breast/chest') (SKS KRA Laihia. Brandt, Herman. 836. 1891 < Amalia Brandt, 32 y. < Sameli Silanpää, Jalasjärvi); however, again, the cancer cannot be divided from other concerns relating to this part of the body. For example, *rintahaava* could also be caused by *ruusu* (erysipelas), described then as the swelling of the breasts (Rytönen 1937, 215).

The facts that allow the differentiation of illnesses in such challenging cases are the treatments and remedies used, although in cases where people were incapable of diagnosing the true causes of illness, they tried various different remedies and healing practices in the hope that something would help. Healing methods were intimately connected with illness origin, which in the case of cancer is again a complicated subject.

## **The problems associated with defining cancer aetiology**

Typically, Finnish folk medicine consists of warning beliefs, sayings and legends advising people against transgressing cultural norms and stressing that they should avoid certain places, times and acts resulting in illness (Honko 1968, 20–23; Hästesko 1910, 324–325; Waronen 1989, 17–18). The Finnish doctor Elias Lönnrot (1802–1884), who was profoundly interested in the Finns and their traditional worldview, described in his medical dissertation how people living in rural society imagined that a person's life was endangered by invisible and visible malevolent forces, always and everywhere (Lönnrot 1984, 190; see also Manninen 1933, 228). According to ethnomedical thought, some of these dangers derived from substances present in the human body, such as blood, sweat, excrements or body hair (Hämäläinen 1920, 133–141), whereas other illnesses were interpreted as acts of human enemies, such as witches and the dead, or attacks of various forms of illness demon (Honko 1968, 23–37). However, such cultural norms and warnings, containing rules of behaviour and preventative techniques for cancer, are not reflected in the available ethnomedical records. In the material at hand I could find only two descriptions of magical practises used to prevent cancer:

*Syöpä estethän tulemasta. Kun lapsia saarhan niin pitää sitte vasta katkaasta navan varrenkun on jo jälkimenotkin alkana, jot' ei sitä saa sisälleen katkaasta, niin sit' ei tuu syöpä lapshen.*

To prevent getting the eater. When the child is born you should cut the root of the navel after the afterbirth is out as well. It should not be cut inside, then the child will not get the eater.

SKS KRA Laihia. Brandt, Herman 1153, 1891 < Amalia Brandt, 31 y. < Anna Pakkanen.

*Sellainen henkilö joka söi käärmeen lihhaa viinapalona tai muuten. Se henkilö ei kuole ruumiinmaun syöntiin eli syöpään.*

This kind of person who ate snakes' flesh as pieces with vodka or otherwise. This kind of person will not be eaten by body-worm or the eater.

SKS KRA Viitasaari. Albert Rautiainen 2768. 1953 < Emil Hämäläinen, b. 1896.

The lack of particular beliefs and norms, as well as preventative techniques, may be interpreted in multiple ways. It may indicate that cancer was seen as an unpreventable illness in the ethnomedical context, where health problems with unknown origins were mainly approached and interpreted as *Jumalan tauti*, referring to generally incurable concerns and suffering sent by God (Naakka-Korhonen 2008, 199–200; Halmesvirta 1998, 50). Although people tried various methods to soothe their suffering, recovery was in the hands of the almighty Father of Heaven. Similar argumentation is also common in cancer patients' pathographies, in which people connect their falling ill with some kind of higher punishment (350, 402, 409).

In contrast to this, ethnonyms such as *vieras*, *ruumiin mato*, *ruumiin koi* or *syöjä* allow the suggestion that cancer was imagined as an individual being, similar to other worm-like parasites such as tapeworm or "tooth-worm", destroying bodies and endangering lives (Honko 1968, 23–37; see also Naakka-Korhonen 2008, 201–202). In cases of tapeworm the worm also existed in reality, whereas, the "tooth-worm" was most likely the greyish-white nerve that was sometimes 'picked out' from a tooth destroyed by caries (Pekkola 2010). In instances of cancer it is not quite clear where the roots of this kind of worm image are, but it is possible to imagine that in open wounds that were not kept clean, maggots would occur.

In addition to this universal disease-worm explanation, in which a putative worm-like disease in limbs or organs is interpreted as the cause of pain (Honko 1968, 23–37), in some

cases falling ill with cancer has also been seen as the result of breaking societal or cultural norms, as defined by the relevant belief system and/or worldview. I wish to emphasise that because of cancer's secondary role in folk medicine, the illness origin was often defined based on single illness cases and thus was closely connected with a personal lifestory. In this vein, one should not forget all kinds of rational causes for the many diseases prevalent at the time, such as malnutrition, exhaustion, unbearable living and hygiene conditions, poor clothing and possibly also untreated injuries and infections (Ackerknecht 1971, 8–21). Similar explanations arising from lifestyle, nutrition or individual behaviour play an important role in current cancer aetiology (see Chapter 5).

The ethnomedical treatments described later in this chapter indicate that the popular aetiology of cancer connects cancer's origin foremost with earth, water and fire. This suggestion is based on the fact that, typically, the ethnomedical treatments are based on *similia similibus curantur* and *pars pro toto* principles (Naakka-Korhonen 2008, 205–207), meaning that the selected treatments are connected with the suggested illness origin. 'Like cures like' means that the selected treatments had to bear a resemblance to the origin of illness or the illness itself, while 'a part for the whole' meant that if part of an illness was taken elsewhere the entire body was healed. Earth, fire and water have mainly been used to heal all kinds of skin problems, and were seen as having the magical power of removing the illness and purifying the affected area. Although there is no apparent evidence for the following suggestion, I still wish to emphasise that in the folk medical context cancer could have been interpreted as a taboo topic because of its unknown origin, lack of effective treatments and of course its connection with images of painful death, and dying in general. The latter perspective becomes particularly important in terms of understanding the ways in which popular attitudes are expressed in written cancer narratives, i.e. the materials under study.

## **Some notions about the medical discourse of the time**

Laura Stark has suggested that, historically, folk belief formed human understanding of the self and its dynamics and balance in a similar way to that in which, today, biomedicine and psychiatry do (Stark 2006, 30). In the case of folk medicine this suggestion could be mistaken for a proposal that folk medicine has inner dynamics based only on folk belief system, excluding other (medical) discourses of the time. It should be emphasised that the

continuous lack of information regarding illnesses, and the poor potential to define the symptoms and offer efficient treatments, made the folk medical system open to all kinds of impacts deriving from other systems (which were not necessarily based on folk belief).

The ethnomedical records relating to cancer offer a good opportunity to demonstrate the relationship between folk medicine and the scientific medicine of the time, a relationship that has for too long been interpreted by scholars of (folk) medicine as being parallel yet without any real meeting points. Again it is worth emphasising that even though the folk medical explanations reflected in the ethnomedical records represent the tradition-based belief system and worldview characteristic of rural Finland, the medical opinions and suggestions of the time, mediated via various publications such as early medical self-help books, calendars and newspapers, were acknowledged, and were also quickly integrated into the existing folk medical tradition. This, in one way, shows the importance of health in general, and in another demonstrates the closeness between medical and folk medical approaches. To exemplify this I shall compare a few examples representing the medical discourse of the time, with descriptions found in the ethnomedical records.

In the medical self-help book *Suomalaisen talonpojan kotilääkäri* (The Finnish Peasant's Home Doctor) first published in 1838, Elias Lönnrot describes cancer and its treatments as follows:

*Syöpäpahka, ruumiinmadon alku. Tutaan leikkelewästä, wiilaisevasta kiwusta, jossa myöhemmin alkaa nähdä suuria sinisiä, suonia ja haawailemia. Myhkyrän ympärille pitää aikaiseen panna 5 iilimatoa joka toinen viikko. Wäli-ajoiksi katetaan se ohuella nahalla, säämyskällä tahi muulla semmoisella.*

Cancer bump (*syöpäpahka*), the beginning of body worm. One recognises it because of its cutting and hurting pain, later one sees big blue veins and wounds. Around the bump one must put 5 leeches every second week. In between, it will be covered with thin skin, turned skin or something similar. (Lönnrot 1981, 109)

A few pages earlier (p. 107) there is a description of how to treat the *koi* (moth), *koiso* (mothy), *wieras* (stranger), *koi sormessa* (moth in finger), *jäsenkoi* (limb moth), *iso kumppali* (big friend):

*Jos olisi alottanut jostaki wieraasta, esimerk. Kynnen alla pistävästä aineesta, niin pitää esinnä sama aine pois otettaman. Muuten imetetään paikka 5:llä eli 6:llä iilimadolla ja haudotaan perästä, koska weri on laannut juoksemasta, 2 eli 3 tiimaa kylmässä wedessä*



*tahi kylmillä puuroilla jouhoista etikan kanssa. Jos tuska ei sillä heittäisi, niin ruwettakoon pitämään lämpimässä wedessä tahi käärittäköön ympäri lämpimiä haudepuuroja ja koska paikka pehmenee, pistettäköön ohut, kaita, terävä weitsen kärki sywältä sisään ja pidettäköön reika auki, kunnes elo lähtee ulos ynnä märeneen luun kanssa, jos sitä olisi. Jälkeenpäin korjataan haawaa lie Wittäwällä woiteella ja sidelaastarinauhoilla. Muutamat neuwawat sian sontaa lämpimältä koin ympäri käärittämään ja sanowat sillä paranewan.*

If [the illness] has begun because of some alien [substance] e.g. something pinching under the finger, this [substance] must be removed. Otherwise one uses 5 or 6 leeches and later the spot must be covered, because the blood has stopped running, two or three hours with cold water or with cold porridge with vinegar. If the pain does not stop then keep it in warm water or wrap it with a warm porridge compress and if the place gets softer one should stab a thin slender knife deep inside and keep the wound open as long as the "life" together with wet bone comes out, if there is any. Later one fixes the wound with some lotion and bandages. Some also advise wrapping warm pig's excrements around the moth; and they assert it cures just as well. (Lönnrot 1981, 107)

This part of Lönnrot's suggestions apparently refers more to problems that are gangrene-like, but considering cancer's ethnonyms the illness could also have been interpreted by readers as some kind of cancer, as is the case in the ethnomedical record regarding *mätänemis viat* (rotting problems) or *koi* (moth) collected from northern Finland in 1907:

*Mätänemis-viat. Koin tuntee [--] hirmuisen kovasta särkemisestä, ihon punoituksesta ja ajettumisesta. Kun koi on ehtinyt pitemmälle, alkaa se syödä sekä luita että lihoja ja tekee ennen pitkää päälle näkyvän haavan joka laajenee ja laajenee ja samalla syvenee luihin saakka, kunnes vihdoin luukin alkaa syöpyä ja kulua kokonaan pois.*

Problems with rotting. One recognises the moth [---] from very strong pain, red skin and its peeling off. If the moth has gone deeper it begins to eat bones and flesh and creates a visible wound that becomes brighter and deeper at the same time until it reaches the bones, so that the bone begins to vanish and finally becomes totally eaten.

SKS KRA E 190 5 Duodecim 479. 1950 < Juho Kantola < Rovaniemi (1907).

Despite difficulties recognising the difference between cancer and other illnesses with similar names, reading Lönnrot's healing suggestions is truly remarkable. Mainly because Lönnrot did not hesitate when suggesting domestic surgical treatments, although he must

have been well aware that poor hygienic conditions among the Finnish peasantry was the cause of many endemic and other illnesses at the time. Notwithstanding this, stabbing the wound is also suggested as a way of finding out if the illness will disappear, and is described in the ethnomedical records examined:

*Syöpää on parannettu siten että on kurinvarras kuumootettu tulipunaiseksi ja sillä pistetty kipii paikkaa. Jos on naskahtanut kun sillä vartahalla on pistetty niin sitte paranee. [---]*

A cancer treatment was used in which one took a knitting needle and heated it red and stabbed the aching place. If it prickled it meant it will be healed. [---]

SKS KRA Kauhajoki. Könnö, Oiva. KT 243: 105. 1939

In his writing, cited above, Lönnrot also mentions the use of pig excrements in the treatment of open wounds, although he seems to have doubts about its usefulness. The internal and external use of all kinds of excrements was widespread in Finnish ethnomedicine. For example, burning someone's excrements gives this person *rupia* (scabs), which together with the magic power of fire can "cleanse" the sick person (Naakka-Korhonen 2008, 206; Hämäläinen 1920, 84–85).

The use of leeches to balance sufferers' conditions was also a common practice among the Finnish peasantry. The idea of cleaning wounds of bad blood derives from Hippocratic ideas on the humours and how they influence the nature and condition of the body (Porter 1999, 58). The idea of bloodletting as a central treatment for any health problems was recognised and adopted both by scientific and ethnomedicine alike in order to expel toxins from the blood. In the case of wounds, leeches were apparently more useful than phlebotomy.

From other written sources we find that a century later, the use of leeches, as per Lönnrot's suggestion, was already seen as unnecessary. The health newspaper *Terveystieteiden lehti* (1912) proposed that instead of bloodletting with leeches, one should use only cold wrappings to control blood circulation (Halmesvirta 1998, 52). Nevertheless, progress towards modernisation and evidence-based treatments in scientific medicine did not greatly affect the situation of those with cancer, as the disease was for a long time still understood as a "body-bump surrounded by a wet wound" (Halmesvirta 1998, 67). This confirms that by the beginning of the 20<sup>th</sup> century, improvements in the diagnosis and treatment of cancer were still minimal. Thus, having cancer would mean suffering and

passing away without much professional help. This, again, put the caretakers into a complicated situation.

Because of the economic and societal situation during the late 19<sup>th</sup> and early 20<sup>th</sup> centuries, accessibility to new treatments was very limited. Only the poorest were supported by law in their efforts to gain access to state supported healthcare (Naakka-Korhonen 1997, 107–110). As any visit to a medical doctor took valuable work time and cost money, people chose instead from the available domestic treatments, or consulted with family members or local healers. As already mentioned, in rural areas, for mainly economic reasons but also due to a lack of faith, a doctor's help was sought only in the worst cases, and even then people often hesitated for the simple reason that buying medicine for someone who was going to die was seen as unnecessary. At the beginning of the 20<sup>th</sup> century, doctors were forced to admonish people, pointing out that helping sufferers should be seen an act of humanity and not be calculated in financial terms (Halmesvirta 1998, 44). Such attitudes demonstrate well the hopeless situation of cancer patients in this period; however, it did not mean that sufferers were left entirely without help.

By the end of the 19th century and the beginning of the 20<sup>th</sup>, general improvements in Finnish society meant that, to some extent, it was possible to alleviate poverty and care for those who were seriously ill. This affected behaviour towards people who were suffering from cancer. For pragmatic economic reasons, attempts were made to place the responsibility for care of the terminally ill with different social healthcare organisations. As there was a shortage of facilities, cancer patients sometimes suffered poor conditions or nonexistent care in houses organised for those in greatest need. Accordingly, in public, because of the lack of money and doctors, people were admonished and encouraged to take care of the sick at home for as long as possible using domestic healing techniques (Halmesvirta 1998, 91–92). The domestic care of the terminally ill naturally reinforced the use of folk medical treatments, which perhaps contained more magic and belief in healing powers than true medical effects. Even today in such cases a patient's strong belief in a given treatments plays a significant role in his or her recovery (see Chapter 8).

The above treatments, suggested by medical practitioners, were used in folk medicine and accordingly are reflected in ethnomedical records, allowing us to see that vernacular perception and scientific medical practice were very close to each other. Such proximity and mutual influence lasted approximately until the advent of the microscope and cancer medicine became a bioscience at the cellular level (Porter 1999, 574–580). However,

before this milestone, particularly when implementing new medical practices, people were eager to experiment with new cures. An individual's health was the most valuable asset for people whose ability to feed themselves on a daily basis was directly connected to their ability to do their daily work.

## Treating 'the growth' and 'the eater'

Archive records indicate that when people recognised cancer, they tried numerous methods to cure the sufferer, and this again has affected the quality of available archive materials. Brief descriptions relate how people tried various curative practices using plants, mixtures, mammal products and magic performances; however, the outcome was always unsure. As with the archive records regarding other issues connected with folk healing, some informants were sure that the practises they used were truly helpful; whereas, others say that despite all efforts it was not possible to save those afflicted (see also Naakka-Korhonen 1997, 85–86). In this context, considering the situation and attitudes described above, it is actually incorrect to talk about healing cancer, but rather about various attempts to treat its consequences.

As cancer was only recognised as problematic once it formed a visible bump or a wet wound, the treatments were mainly divided into two categories meant to cure either the closed or the open wound. These wounds were generally treated either by salving (*voitelu*) or pressing (*painelu*) the affected area. For salving, different substances were used, most of them available in the domestic sphere, such as vodka, dirty water, water, the sweat from glass (condensation), or water from a hole in a stone; although urine, spit, salt, turpentine (*Aetherolum terebinthinae*), lamp oil or mercury were also used. Various plant-based liquids were prepared using herbs and other plants like *tulikukka* (Great mullein, *Verbascum thapsus*), *maitikka* (cow wheat, *Melampyrum*), *näsiä* (mezereon, *Daphne mezereum*), *tuomi* (bird-cherry, *Prunus padus*), *suokanerva* (wild rosemary, *Ledum palustre*), *tielehti* (plantain, *Plantago major*), *ryssänlehti* (*Mahorka*-tobacco, *Nicotiana rustica*), *inkivääri* (ginger, *Zingiber officinale*), and *pippuri* (pepper, *Capsicum*). Here, when considering various healing plants and herbs, one must be aware that the ethnobotanical plant names referred to in the ethnomedical records are not necessarily in direct correlation with plant taxonomy as we know it today (Kalle 2008, 53f.; see also Naakka-Korhonen 2008, 209).

Among the healing plants are juniper and the birch tree. The latter was used when boiling the *tuhkalipeä* (birch-tree ash), perhaps the most well known cancer medicine in the Finnish context, containing water and ashes from the birch tree. For example, among the answers received in the 1978 folk medicine collection, we find the following suggestion for the preparation of *tuhkalipeä*, which in diluted form was supposed to help maintain a patient's general health by increasing low pH levels:

*Koivuntuhkalipeä (1 osa tuhkaa, 5 osaa vettä kiehautetaan; sakan annetaan painua, kirkas neste päältä pulloetaan; käytetään vajaa ½ dl 3-4 kertaa /p. kaljan, piimän tai limonadin kera).*

Birch tree ashes (boil 1 part ash with 5 parts of water; let it settle, put the clear water into a bottle; one takes half a decilitre, 3 to 4 times a day with beer, sour milk or lemonade.

Kansanlääkintäkysely 1978 – Liminka. Paavo Kytökorpi 18.

Together with blueberries (*vaccinium myrtillus*), which contain useful antioxidants (Kansanlääkintäkysely 1978 – Suoniemi. Arto Järvensivu 206, see also Blueberries Health), the “fluid of birch tree ash” has survived as a well known cancer treatment to the present day, and is used by cancer patients as alternative or complementary medicine (Gernet 2009 & Keskustelut, Koivuntuhkalipeä ja syöpä 2005).

Mixing different plants and substances containing putative magic and healing powers is typical to folk medicine. By doing so people believed they could make medicines even more powerful. It is not extraordinary that such healing potions were used internally and externally at the same time in an attempt to push and pull the illness out of the body:

*Paratahan syöpä rinnoosta: Kun pannahan puoli naulaa koiran rasvaa ja puoli naulaa ryssänlehtiä ja tuoppi vettä patahan. Se sitte kiehutetaan; niot' ei jää kun puoli tuoppia vettä patahan. Sitte kun soon jähtynyt niin siihen sitte pannahan puoli tuoppia viinaa. Sitte se pannahan tallellen pottohon. Sitte kun sitä ryyppäjää puoli kantakupillista joka huomen, niin paranoo syöpä rinnoosta, jos on syöpä johonkin rinnoos.*

To cure cancer in the breast: you put half a pound of dog fat and half a pound of mahorka leaves and a pint of water into a cauldron. Then you boil it until there is only half a pint of water left in the cauldron. Then, as it is cools down, you add a half pint of vodka. Then you close it into the pot. And then you drink a little cup of it every morning and so the eater in the breast will be cured. If there is an eater in the breast.

SKS KRA Laihia. Brandt, Herman 1153. 1891 < Amalia Brandt, 31 y. < Sameli Sillanpää, Jalasjärvi.

As dead people were believed to interfere with the lives of the living by sending them various suffering, the substances connected with the dead corps had a practical value in folk medicine (Rytönen 1937, 213). Accordingly, the water that was used to wash a dead body was believed to have healing power, *väki* (Naakka-Korhonen 2008, 84–86) and was therefore also used in treating cancer wounds:

*Kertojan vanhoilta kuulemma taika uskomus. Myöskin käytettiin ruumiin pesuvettä ja ruumiin saippuaa n.s. ruumiin koita (syöpää) parantaessa, pesemällä niillä syöpä kohtaa.*  
An old belief that the storyteller has heard from older people. The water that was used to wash the dead body, and also the soap, were used to treat the body moth by washing the cancer place.

SKS KRA Sortavala, Otoisten kylä, Hyvärinen, Juho KRK 141: 482. 1936 < Maija Hyvärinen b. 1905.

As with the treatment of many other skin problems, people also used earth from graveyards as it was believed to contain power emanating from the dead. Here, as in many other similar rituals, it was important that the intermediating earth was returned to the graveyard after use:

*Syöpätauti jos vaivasi niin haettiin hautausmaalta multaa ja hierottiin sillä, jonka jälkeen se vietiin takaisin hautausmaalle samaan paikkaan niin syöpä parani.*

If someone had the eater illness then one brought earth from a graveyard and rubbed the ill place. After use, the earth had to be taken back to the same place from where it was taken.

SKS KRA Pori. Porin tyttölyseo, 2934. 1936 < Simo Konttinen, b. 1901.

In a similar manner, people also made use of stones, tree knots, ears of grain and wooden sticks to press the illness out of the body (see also Palmén 1937, 231–232). Stones, knots, sticks and other magical items were used as intermediating agents that were believed to take on the illness and therefore, like graveyard earth, were handled with care to avoid new infection. The number of intermediating agents was also significant. The typical magic numbers were 3 and 9 (3x3), so for an effective cure people took, for example, 3 stones (SKS KRA Ritola, Jaakko. VK 81: 10. 1909 < Antti Hintta) or 9 kinds of grain (SKS KRA Kalajoki. A. Lindqvist 237. 1887 < Miina Alstetti, 40 y.) or spit from 9

different people collected in the morning (SKS KRA Ii. T. Matikainen 317. 1906). The rituals involving intermediating agents were typically repeated three times to assure efficacy:

*Painellaan kivellä kolme kertaa, se painuu. Ei tavallisella kivellä. Konovitsan kivet on hyviä, samoin esim. rillirauta. Kierretään sillä kaaressa.*

One must press with stone three times, then it gets lost. Not with any stones. The stones from Konovitsa are good, but also for example [?] iron. You make a circle with them.

SKS KRA Rautu. Haavio, Martti 80. 1931 < Annuska, Tatjana Haukan naapuri, 60 y. Mp. 1921.

Another method to improve the power of ethnomedical practices consisted of various rituals in which curative methods were combined with the use of animal blood, ashes, flesh, fat, and excrement. This examples suggests the following:

*Parannus syöpää vastaa saadaan kun ottaa elävän kravun ja sitoo sen kynnet yhteen kiini niin että se ei saa nipistettyä sitte ottaa se ravun ja panee sen sen kipiän paikan päälle ja antaa sen olla siinä niin kauvan kuin se siinä itsestään kuolee vallankin jos ei syöpä vielä ole auki oleva niin on tämä paras keino ja muutenkin se auttaa se on tosi.*

To cure eater you take a living crab, tie its claws together so it cannot pinch you, and put it on the aching spot. You let it stay there until it dies. This is a particularly good method if the cancer [wound] is not yet open, although it helps otherwise. It is true.

SKS KRA. Kiikala. Lindqvist, Aleksander 388. 1891 < Gusta Helgreeni, 60 y.

*On syöpää vastaan se kun ottaa vasta tapetun kyyhkysen ja halkaisee sen ja sitoo ne puolikkaat kumpainenkin jalkapohjan alle mutta samalla täytyy myös panna vasta tapettu rotta sen paikan päälle jossa syöpä on niin se kuljettaa säryyn jalka pohjain kautta pois.*

Against eater one takes a freshly killed dove and cuts it into two halves and ties these halves under the soles of the feet, but at the same time one must also put a freshly killed rat on that place where the eater is, so it takes the pain out though the soles of the feet.

SKS KRA Loimaa. A. Lindqvist 498. 1892 < Liisa Härkönen, 71 y.

Because of the belief in the eater or the moth as a worm-like illness, one popular animal product to heal cancer was a mash of earthworms (SKS KRA Virrat. Eino Mäkinen 6, 1936 < Lydi Hietanen. 405; SKS KRA Viljakkala. Mattila Martti E. 3810. 1936 < Jeremia

Hieturi, 82 y.). This product was prepared in different ways, but the main aim was to change it into a salve so that it became possible to smear it on the cancer wound:

*Syöpä paranee kun ottaa tyhjän sarvej ja panee sen täyteen onkimatoja ja pään kii. Kun sitte sen sarven panee saunan kiukaaden niittä se saa siä kiahun rasvaks ja siellä rasvalla usein voitelee nii kyllä syöpä paranee.*

You can heal eater if you take an empty horn and fill it with earthworms and close it. Then you place this horn on the sauna stove so it boils and becomes a fat, and if you salve with this fat often enough then the eater heals.

SKS KRA Tattijärvi. Jukka Rehola 319. 1904 < Herman Piitamaa, 70 y.

Within Finnish folk medicine, selecting the right place and the appropriate time had great significance for the successful outcome of healing rituals. Generally speaking, this meant preferring a certain day of the week, such as Sunday, Tuesday or Thursday, and avoiding Wednesday and Friday (Palmén 1937, 231). Usually the selected time, early morning, midnight or late in the evening, was decided on so that there would be no occasional people passing by, as there was a fear that any stranger might cause additional harm or make treatment invalid.

The ethnomedical records on cancer allow the suggestion that the particular time, and also place, were more important when treating what were called *kasvaja* or *kasvi* (external growths). Here, again, it becomes difficult to separate the treatment of cancer growths from other skin problems, such as warts, allergies or boils, which, according to folk belief, originated from the earth. Normally, treating various external growths, whether cancer or not, meant taking account of the phases of the moon, thus creating a connection between the growing and diminishing moon and a growth which, although it that may have been getting larger, was expected ultimately to disappear.

Typically growths were pressed with earth, knots, or sticks from particular trees taken at the time of the new moon. This practical *ars magica* was supported by simple sayings, like: “*Painu, elä paisu, ja pane puuro päälle!*” “Get lost, don’t grow, and put some porridge on.” (SKS KRA Heinävesi, Varistaival. Pennanen Olavi KRK 84: 441. 1935 < Anna Maria Törrönen b. Koponen, 67 y.) Or with more powerful spells in the following manner:

*Tautien painelus. Pahkat painan, kuvut kuristan, kuun kuulumattomaks, päivän näkymättömäks, kun et kuluu kuuna päivänä, etkä nävy ilmaana ikänä, linnat liikkuu,*



*järvet järskyy, mikset sinä liiku? Paha, pagene pois ennen päivän nousemista, auringon kasvazzumista.*

Pressing diseases. Warts I press, bumps I strangle, away from the moon's hearing, away from the day's seeing, if you don't disappear in a month, and don't shrink in time, towns move, lakes shuffle, why don't you move? Bad one, get lost before the day rises and the sun grows.

SKS KRA Impilahti, Ruohojärvi. Saarela, Niina, 18 y. KRK 153: 114. 1935.

Thus it was assured that by selecting this particular time for healing, as the new moon stopped growing, so also the growth would vanish for good (Naakka-Korhonen 2007, 86–87). In this context, trees also appear as a metaphor for a tumour, which was imagined as being hard like a tree knot and as having stumps or roots that had to be removed in order to cure the cancer. The tree metaphor is also used in healing charms that describe how the growth should disappear inside the tree rather than torturing humans (SKS KRA Suistamo. Hautala, Jouko. 1078. 1939 < Sandra Lösönen, 78 y.). Such metaphoric connections between cancer and the various images of trees is very strong in people's minds even today, and is also repeated in cancer patients' narratives (see Chapter 6).

The most common places for healing were the doorstep, crossroads, graveyards, as well as other places that were believed locally to have a certain closeness to the spirits. Additionally, such places as chimneys, thresholds, pigsties and the forest near the household were seen as suitable places for dealing with all kinds of magic, including curing various illnesses (Hämäläinen 1920, 102; Palmén 1937, 232; Paal 2004, 99–102). Perhaps the most important healing place in the Finnish context, particularly for healing growths and other skin problems, was the sauna (Naakka-Korhonen 2008, 210–213; Hakamies 1983, 277–279) as it offered direct, private, access to earth, water and fire, all recognised as the most important substances in the treatment and pressing of different kinds of growths and lumps:

*Ihosityöpä. Tässä tapauksessa käytetään tulen voimaa. Se saadaan siten, että tietäjä menee saunassa kiukaan, muurin pesään pää edellä, jossa hän salaperäisesti hymisee: "Tulen voima, tule tänne." Sen tehtyä ottaa hän kiukaasta kolme kiveä, sylkäisee kolmasti joka kiveen, painaa kolmasti joka kivellä samaa kohtaa aina niin kauan kun auki olevat paikat ovat tarkkoihin joka paikasta painellut, jolloin hän viimeisellä kivellä painaessa koppaa sairasta kiinni ja karjaisee haltioissaan: "Pois paskat." Sitte hän asettaa itse kunkin kiven siihe paikkaan, josta ne otettu oli.*

Skin cancer. In this case one uses the power of fire. This is made as follows: the healer enters the sauna oven humming secretively: “Fire-power come here.” After doing this he takes three stones from the sauna oven, spits three times on every stone and presses the same place with every stone, as long as open wounds are carefully pressed from every side. Then after trampling with the last stone, he grabs the sufferer and screams in trance: “Off the crap!”. Then he puts all the stones back in the places where they were taken from.

SKS KRA. Ritola, Jaakko. VK 81: 10. 1909 < Antti Hintta.

The tradition of using different remedies and rituals at the same time makes it difficult to give a proper classification of folk medical cancer treatments. As I already suggested, for domestic healers the most important act was finding the illness origin and then selecting suitable curative practices. Based on the ethnomedical records that describe different healing practices, it is only possible to suggest the supposed illness origin and the aim of selected treatments. The herbal remedies used suggest that the eater or the moth were seen as independent beings – disease worms. This is shown by the use of the same strong-smelling herbs that were used in the Christian tradition of exorcism (Valk 1994, 149). This idea is supported by the use of all kinds of mixtures, lotions and mammal products, as well as herbs, described in the ethnomedical records. While salving and pressing may again be interpreted as parts of a healing ritual that raise magical power on the one hand, on the other they may also be seen as methods of balancing body dynamics and correcting the endangered physical order. Here particularly, earth, water and fire are used as intermediating objects that remove disease from sick bodies. The verbal healing used in the domestic sphere may be interpreted as playing an important role in all kinds of other curative practices (Palmén 1937, 227).

## **Gaining healing power**

Although people knew shorter magical sayings and charms, more powerful healing was typically practised by the local specialist *tietäjä* (‘the one who knows’). The central idea in any healing ritual was to send afflictions back to the place of their origin and balance social disorder (Honko 1993, 365). Accordingly, in the healing ritual the healer aimed to dispel illness from the patient’s body by diagnosing the origin of the illness. With the help of magic rituals united with the power of words, the illness was forced to leave:

*Lihansyöjä, kuivakkah,  
 luunpurija puurtukkah.  
 Lihansyöjä, luunpurija,  
 jäsenien järkyttäjä,  
 kuin lienet kotini koiria.  
 Syö sie luita lautsan alta.  
 Vain kuin lienet kyläni koiria.  
 Syö sie luita pellon peässä.  
 Mäne heitto helvettiin,  
 häikie häpiemähä.  
 Syömästä kaluomasta!*  
 SKS KRA. Paulaharju, Samuli 4350. 1911.  
 Vuonninen, Oulu.

Meat eater, dry one,  
 bone biter, screwy one.  
 Meat eater, bone biter,  
 limb torturer.  
 If you are a domestic dog  
 eat bones under the table.  
 If you are a village dog,  
 eat bones at the edge of the fields.  
 Go fast to hell,  
 get lost to shame.  
 Away from eating, aching!

When the local healer was asked to help the healing act in some way, this act immediately took on a different value, as in the following example:

*Haapavedellä siellä 1929 koetettu syöpätauti parantaa "haltian voimalla". Syöpä tautisen luokse tullut Alatalon Niika – katsonut sairasta ja yhä enemmän haltius kohonnut. "Ei sinussa ole muu kun Martti-vainaan pirut." Sairas kieltänyt halteutumisen. Sairas kuoli parin viikon kuluttua.*

In Haapavesi they tried to cure the eater disease with the 'power of the spirits' in 1929. Niikka from Alatalo came to the diseased one and he looked at the ill one and the spirits rose. "There is nothing in you other than the devils of Matti the dead one." The ill one refused to be healed and died a few weeks afterwards.

SKS KRA Muhos. Marttinen, J. 1625. 1931 < H. Korpikallio, 58 y.

*Joensuun Sohvi loitsi veljeni ranteesta kasvannaisen. Alakuun viimeisenä päivänä hän pani sen päälle tähkiä ym., paineli sitä molemmiin peukaloin ja hoki: "Syö kuu kasvannaista, kasvannaisen kantaa."*

Sohvi from Joensuu charmed off the growth from my brother's wrist. On the last day of the waning moon she put ears of grain and some other stuff, pressed it with both thumbs and said: "Moon eat the growth, [eat] the growth's heel."

SKS KRA Saarijärvi. Harju, Otto. 433. 1938 < Aukusti Kyyrä, b. 1867.

The different value here refers to the fact that accounts of healing in which recognised healers were involved, tend to concentrate on the healer's personality and healing skills, and less on healing practices and final outcome. The local healer was a respected person who maintained the role of healing specialist. However, all healers were not equal in their status, skills and powers (Siikala 1992, 71–76; Kopponen 1976, 8–9). This meant that when there was a growth, or the eater, one had to visit the healer who had a special talent for removing specifically these ailments.

Among the studied materials I discovered two texts saying basically that anyone could gain the power to heal growths or the eater after performing certain rituals:

*Litomadot ovat hyytelömäistä melkein kuin sammakon kutu. Kulkevat käärmeen muotoisessa parvissa. Tarkasti katsomalla erottaa pienoiset mustat päät ja ruumiin ääri viivat jotka ovat limalla toisiinsa yhdistetyt ja kulkevat jokainen ruumistaan liikutellen kulku on niin hitaasta ettei se näytä juuri ollenkaan estyvän. Näitä hämmennellen on moni saanu taika käteen jolla painellen kasvannaiset ihmisruumista painu. Nytki elää vielä sellaisia poppamiehiä. Näitä matoja ei ole nähty vuosikymmeniin.*

Lamprey larvae are like jelly, like frog's spawn. They go like snakes in a cloud. If you watch carefully you can separate little black heads from their body contours, which are connected with others by slime, and they go slowly moving their bodies, although their movements are so slow that it looks as if they are not going at all. If one stirs them, this person gets in his hand the magic to press growths, which then disappear from the human body. Even nowadays you find such healers. Those worms one has not seen for ages.

SKS KRA Peilisjärvi. Hiljainen Hanna, KRK 156: 27. 1935.

*Jos joku alastomalla kärellään käy kiinni Myyrään keskeltä ja pitää sitä niin kauvan siinä kuin se kuolee niin saa se käsi sen voiman että hän voi parantaa kaikkia syöpiä ennen kuin ne pahoiksi kerkiä tulemaan kuin hän vain tällä kärellä muutamana kerran sivele kipeetä paikkaa.*

If someone holds with a naked hand a mole from its middle and holds it there as long as it dies then this hand gets this kind of power that one can heal all eaters before they can turn bad, even if he only touches the aching place.

SKS KRA Kiikala. A. Lindqvist 389. 1891 < Gusta Helgreeni, 60 y.

In both examples, the magic power to cure illnesses like growths or the eater is gained via animals and positioned in the hands. Healing with hands has been one of the central acts in folk medical treatment and thus the powerful touch of the human hand also appears

in charms (Piela 2005, 11f.; Honko 1994, 37). As the following example shows, it was also thought that if human hands could not cure a patient, God's hands could:

*Nouzen ja painelen,  
kazvajaj kavottelen,  
kuun kuulumattomah,  
päivän nägemättömäh,  
kus et kuluu kuuna piän,  
sinä ilmosna igänä.  
Puun juuret punottumah,  
koivun juuret korguomah,  
hoavan juuret hajottumah  
pajun juuret painumah,  
vaan ei ihmisen iho.  
Linnat liikkuu, järvet järskyy,  
vuoret vaskizet vabisou,  
linnan torit torskahteloo,  
kun et kuulu kuuna piän,  
nävy ilmosna igänä,  
miun käzien käytyvö,  
miun sormien sobivuo.  
Jos ei käyne miun käet,  
sobine miun sormet,  
sit käygäh Luojan käet,  
sopikkah Jumalan sormet,  
itse Luoja loitssemah,  
pyhä isä pistämäh.*

I stand and press  
the growth I reduce  
away from the moon's hearing  
away from the day's seeing  
if you don't disappear soon  
you appear again.  
Tree roots intertwine  
birch tree roots tower above  
aspen roots dispel  
willows roots descend  
but not human skin.  
Towns move, lakes shuffle,  
copper mountains shake,  
town markets sound  
if you don't disappear soon  
don't shrink in time,  
I shall use my hands,  
I shall try my fingers.  
If my hands can't do it,  
my fingers can't handle it,  
then the Lord's hands should do it,  
God's fingers should handle it,  
the Lord should charm,  
the holy father stick in.

SKS KRA Suistamo. Hautala, Jouko. 1078. 1939 <  
Sandra Löönen, 78 y.

Removing illness from a sick body and transmitting it to these agents caused the agents to become new carriers of the disease, and thus they were seen as highly infectious. The idea that illnesses could have been transmitted via different substances shows how, in folk medicine, these illnesses were interpreted as infectious. Therefore, bodily contact with sufferers must be seen as a complicated issue. Placing the hands over the possibly infectious site required certain protective power that was not given to everyone. It is also

notable that healing with the hands is still practised among modern cancer patients. According to the cancer narratives, this may be a simple self-suggestive act practised at home alone (031), or offered by a particular specialist *henkiparantaja* (spiritual healer) often representing a religious movement (186). These examples show how both in the past and today, those other than designated healers refrain from touching cancer sufferers when attempting to help them, meaning that non-specialists have historically, and continue to be, afraid to touch cancer patients. I shall return to this subject, which is linked to the contagious image of cancer, in various contexts in later chapters.

## Conclusions

Based on the ethnomedical texts included in this study, I suggest that people in rural Finland did not have fixed ideas about cancer and its symptoms. Such uncertainty makes it a challenge to decide which problems were handled as cancer, and which ethnonyms refer to cancer. My attempts to understand this situation made it clear to me that while impressions can be drawn from the information, intuition plays its part in the process. Notwithstanding, this chapter attempts an overview of popular ideas regarding cancer and its healing in Finnish folk medicine in order to create historical frames of reference within which to understand current popular images of, and beliefs about, cancer.

It is worth emphasising that cancer did not belong among the primary concerns of the Finns until the era of modernisation within medicine, which began in approximately the 1960s. This impression is supported by cancer patients' narratives, which include individual reminiscences of cancer during the first half of the 20th century:

*Ensimmäinen tieto tästä sairaudesta minulle tuli, minun ajatusmaailmani, kun keväällä v. 1931. N. N. Kemin Vainikkalan kylästä kuoli syöpään. Hän oli naapurin mies, sellainen rakennustyöläinen. Minä näin hänet sairaana, hän oli luonnottoman kalpea, ja laiha, kotona hän sairasteli. En muista varmasti, mutta vatsassa se kasvi taisi olla. Se oli hyvin kauheaa, ei oltu kuultu sellaisesta taudista, en ainakaan minä. Ei siitä osattu ainakaan parantaa. Seuraava oli oman kylän vanha-isäntä Taavetti Vainikka, samanlainen sairaus hänessä ja kuolema keväällä 1938. Eihän ne kylän isäntien kuolemat nyt muuten minulle paljon merkinneet, mutta kun Vainikan tytär Vieno oli ikätoverini, niin taisinpa hänen kanssaan vähän itkeäkin, osaa ottaen. Sitten niitä alkoi kuulua yhdeltä ja toiseltakin puolelta, sama sairaus monella tutulla. Ja sattui kohdallekin.*

My first reminiscences of that illness came into my worldview in the spring of 1931. N. N. from Vainikkala village in Kemi died of cancer. He was our neighbour, a construction worker. I saw him when he was ill. He was unnaturally pale and thin. He was at home. I do not remember correctly but I suppose the cancer was in his stomach. It was terrible, no one had heard before about this kind of illness. At least I had not. No one could heal it. The next one was T.V. from our own village. He had a similar illness and he died in 1938. These deaths did not have any particular meaning to me. As T.V.'s daughter was my age, I believe I cried in sympathy with her. Since then I have heard from here and there about cancer and many acquaintances fell ill with it, and then it happened to me. (047)

The available statistics, compiled by medical practitioners, shows that cancer did not belong among the most significant illnesses of the time. Above all, trained doctors recognised breast cancer and skin cancer, although of course this does not mean that other cancer types were nonexistent. Folk medical definitions, such as 'stomach illness' or 'lung illness', or other vaguely defined health problems, could all be caused by cancer; the problem was that, like village people, trained doctors also failed to diagnose cancer because of a lack of the correct resources. Therefore, it seems appropriate to propose that cancer's current place among other modern illnesses has been constructed in parallel with the development of modern medicine.

This parallel development has, at least so far, not changed the culture-bound images associated with cancer. As I shall demonstrate in the following chapters, people still picture cancer as a living being endangering human life. Because of its often inexplicable origin, people share various theories about its aetiology. This also means that often enough cancer is interpreted as a consequence of sometimes widely differing causes, such as individual lifestyle, personal qualities, or the various environmental effects of the Chernobyl catastrophe in 1986 and even unhealthy underwear. Based on the ethnomedical records it is possible to suggest that cancer has been seen as an infectious disease and thus people without particular skill tried to avoid bodily contact with those affected. This, in my opinion, explains the fear some people still sense when in contact with cancer patients. The only thing that modern medical practice has changed entirely are the healing practices. This makes it even more interesting to examine how traditional ideas are interpreted, accepted and put together in cancer patients' writing about their lives after diagnosis of the disease.

## **4 The Cancer Narrative as Dialogic Imagination**

The language of every cancer narrative reveals an astonishing variety of attributed or assumed meanings that appear particularly significant in cancer (Teucher 2003, 1–2). Understanding the importance of structural principles when analysing written texts is not enough if we wish to comprehend and examine the author's intended meanings, implied in written texts. In this chapter I wish to demonstrate how the respondents operate with individually significant issues and themes within the context of the writing competition. For this reason, I concentrate on two significant aspects in written cancer narratives: the structural segments and authorial speech. I suggest that where narratives become finalised according to structural principles common to our culture, the author's intended meanings also become explicit (Hymes 1985, 395).

I approach cancer narratives as thematically united wholes in order to point out the characteristic features of form and content that are present. I have selected three cancer narratives as examples of how cancer narratives are structured and why such structures appear. My particular interest here, and throughout this thesis, is in the self-expressive techniques used to make the writer's primary intentions (tendencies and goals), or intended meanings, meaningful to receivers. With this in mind it is important to note that the potential explicitness of cancer narratives is above all connected with people's culture-bound understandings of the expectations connected to the process of being ill. I suggest that in order to be meaningful, a cancer narrative's structure must follow the culturally accepted course of illness, which begins with diagnosis, is followed by treatments and ends with recovery/death, whereas, the materials under investigation here point out that the course of cancer is never predictable. In reality the course of the illness is often full of unexpected turns, frequently ending without a clear outcome. Narratives, however, mainly in order to make sense, must follow the rules of narrating, and accordingly in the stories composed the illness process must have a certain beginning, middle and end, or it loses its explicitness and significance.

Mikhail Bakhtin has proposed that all utterances have a responsive character (Bakhtin 1981, 280). The statement on the responsiveness of cancer narratives points out that the respondents, while composing their narratives based on personal experience, have to consider (or at least be aware of) the expectations of potential recipients. In the context of the archival writing contest, such expectations are initially defined by open-ended



questions (Latvala 2005, 80). Furthermore, writers consider the archive's more general function within society, a function that is bound to traditions of collection and preservation. Ulla-Majja Peltonen has suggested that "the institutionalised collecting of tradition gives the received materials an organised value, which also means that without the writing competition many people would not have succeeded in writing down their experiences and reminiscences" (Peltonen 1996, 62). With cancer experiences the institutional role of the cancer associations, as the dominant party in organising this particular writing competition, becomes clearly evident. Respondents are aware that cancer patients' associations stand in the first place for patients' rights. This explains, for example, the criticism typical in cancer narratives of the physician's role in the healing drama, and of the time spent in hospitals and the socially supported healthcare system in general; whereas in other stories people express their gratitude towards doctors for saving their lives and appreciation for the work done by cancer associations in supporting patients. In oral narration, these tendencies are recalled following demand from an audience, which on the level of metanarration aims to bind the storyline and its message (Kaivola-Bregenhøj 1996, 162–164). Accordingly, we may argue that the general structure of the received texts is to some extent influenced by open-ended questions that for writers express the primary expectations of their audience.

In the previous chapter, I argued that composing a narrative is a combination of many factors. Unfortunately, when dealing with written text we cannot be sure which factors have affected the author most. In his study on authorial speech occurring in written texts, Bakhtin proposes that for the author, the language used in writing has intentional dimensions, whereas, for outsiders the words, expressions, described events and expressed ideas become objects (Bakhtin 1981, 289). Despite its changed 'object-like' status authorial voicing (Hanks 1989, 113–115) is used to describe distinctions in an author's status within a text, making it noteworthy in many ways. I emphasise that paying attention to authorial speech and voicing(s) may help to find answers to the questions posed in writing this thesis: how do people express their ideas, thoughts and feelings regarding cancer, and why so?

To better understand the dialogic imagination and the change in authorial speech emerging in written cancer narratives, I use Bakhtin's idea of 'chronotope', defined as the place where the dialogic voices appear and where the "knots" of written narrative become "tied and untied" (Bakhtin 1981, 250). Foremost, these knots refer to times and places that are significant in terms of the events described. The author moves from one event to

another by binding the time and place in his or her story, which in addition to individual meanings that become expressed in the text, make the composed narratives acceptable in terms of cultural expectations. According to Bakhtin, chronotopes provide the basis for distinguishing generic types in secondary genres, but as any language or literary image is chronotopic, spatial categories bound in temporal relationships equally mediate the root meanings of the text (Bakhtin 1981, 250–251). Accordingly, I demonstrate how thematic writing indicates a writer's inner argumentation and how this process may be interpreted as an intended negotiation between the author's individual voice and culture-bound ideas about cancer. By applying William Labov and Mikhail Bakhtin's significant theories about the forms and intentions characteristic to written self-expression, I will endeavour to highlight the dialogic imagination of the authors' intentions within the pre-set and defined frameworks of tradition, and in particular the writing competition at the heart of this thesis.

## **The text selection criteria**

The cancer patients' responses to the archive's request have different qualities. In fact, all the stories are different as they have an idiosyncratic nature. Therefore, it is difficult to decide which narratives should be selected for close analysis, and to be used to represent the text corpus as a whole. Not only the literary quality, but also the varying lengths of the responses is problematic. Apparently it is not beneficial to analyse and compare responses that are only a single page long with those containing fifty or more pages. It is equally problematic to decide how many texts would be enough, in terms of adequate results illustrating the intended interpretations of the texts. In their uniqueness, cancer patients' narratives exemplify how the individual cancer experience, its meaning in personal life and its written interpretation, are largely dependent on patients' past experiences and their expectations of their lives to come. It seems surprising that the received texts, which tackle unique experiences (perhaps never before expressed in any context), contain related themes and even use similar argumentation techniques. An understanding of particular cultural settings seems essential in order to make cancer narratives responsive, or to fulfil the expectations of the competition's organisers and other potential receivers. Therefore, it is interesting to examine how, when and why respondents employ similar culture-bound reasoning and self-expressive tools, and in which settings the personal experience dominates over culturally set boundaries.

After considering the general scope of this study, I decided to pick three texts for further examination. I am aware that this is a very small number compared to the whole text corpus, however, I believe that the writing competition texts presented in their full length help us to get a glimpse of what such writing is like. Unfortunately, no structural analysis method exists that would allow the replacement of the original text without losing its original wholeness: selected words, expressions, events, etc., which make the stories' intentions graspable. The selected stories are presented in their full length in Finnish with comments in English referring to particular episodes. The English translations are in Appendix 2. Although the participants have given permission for their texts to be published, for ethical reasons I have changed their names and replaced other names mentioned in the stories. I have also changed the dates.

The first text was composed by Seth, who was diagnosed with pancreatic cancer when he was 29 years old. His cancer story begins at the beginning of the 1980s. The second cancer narrative was written by Hanna, who got to know about her ovarian cancer when she was 30 years old and the mother of a six-month-old baby girl. The third story was written by Ruth. She was 46 years old when a telephone call from the hospital suddenly made her a melanoma patient. The reason for the selection of these cancer narratives lies in the following criteria: the respondent's age when falling ill, cancer type, the length of the pathological drama, the patient's geographical location and the development of the cancer.

For the first two respondents, falling ill with cancer in their early thirties seems somewhat unrealistic. Having cancer does not fit into their lives, which are full of plans; they feel as though they are just beginning. In this sense the third patient, Ruth, represents the more typical cancer patient: an adult with a grown up child, although she is still not old enough to consider cancer as a normal part of growing old. As the analysed stories point out, falling ill with cancer comes to every respondent as a negative surprise, changing the course of life in many ways.

The second reason for selecting these particular narratives is that these stories represent different cancer types: pancreatic, ovarian and melanoma, which are rather common among Finns. My aim in presenting stories dealing with different cancers is on the one hand to demonstrate cancer's uniqueness on an individual level, and on the other to point out the similarity of the concept of cancer in popular reasoning. Although pancreatic, ovarian and skin cancers occur in different body parts and tissues, all of these are referred to using the meaningful word *syöpä* (cancer).

I also selected stories that would reflect the period of the 1980s and the beginning of 1990s. Firstly, this period is well represented in the text corpus, and secondly, selecting stories from the same period gives better grounds for comparison, as the biomedical settings are similar. A slight change in medical discourse is still graspable though, as Seth's story goes back to the beginning of the 1980s, Hanna's cancer experience began at the end of 1980s and Ruth's melanoma story occurred in the 1990s.

The story events take place in different regions. Seth and Hanna's illness stories take place in the area of the capital, while Ruth comes from a smaller town.

Finally, a unifying strand for the selected stories is that Seth, Hanna and Ruth are all survivors. To use the words often repeated in cancer narratives, when writing their stories all of them enjoy the *jatkoaika* (continuation time) or *armo aika* (mercy time) given to them. These three respondents have all experienced cancer starting with the pre-symptomatic stage and continuing until the post-recovery period. They have gained knowledge of cancer, have experienced returning to be among 'normal' people and everyday duties, and have had at least some time to analyse the significance of cancer in their lives, before putting their experiences down on paper.

I suggest reading the following texts carefully as this will help in understanding the forthcoming chapters, in which I continue to analyse the meaningful 'voicing' characteristics present in the narratives. Within the texts I have underlined some parts and some expressions in order to point out the words, expressions and primary narratives that are meaningful within the text corpus as a whole. The occasional capital letters occurring in the texts belong to the original writing. Regarding the structural elements containing the knots of time and place, I have divided the stories into analytical episodes. The number of each episode is given in brackets (1, 2, etc.). I have also used comments in brackets [comment] to draw the reader's attention to textual units which, in this thesis, gain a significant value in the interpretation of written cancer narratives.

### **Seth's story: *Muutamia haja-ajatuksia ja muistoja syövästä* (Some indistinct ideas and reminiscences on cancer).**

[the moment of diagnosis]

[1] "Ohoh, tästä tulee leikkaus aivan varmasti", kuulin lääkärin hämmästyneen lauseen takaani. Makasin poski likistyneenä poliklinikan tyynyä vasten, rektoskopiaputki peräpäässä. Lääkäri katsoi siihen kuin kaukoputkeen, sisäavaruuteen. Hämmästys, melkein säikähdys lääkärin äänessä antoi minulle helpotuksen tunteen. Pitkä henkilökohtainen painajainen oli ohi. Jotain oli

	<p>todettavissa asiantuntijan silmin. Epätoivo, tuska, unet, avuttomuuden tunteet eivät olleet olleet vain minun huonommuutta tai kuvittelua. ”Täällähän on kasvain, vielä ei osaa sanoa minkä laatuinen, mutta verta valuva se on”, jatkoi lääkäri. Tiesin, että se oli pahanlaatuinen. Olin tuntenut sen tarpeeksi kauan. Huojennus, kuukausien vaiva kivulloisten peräpukamien kanssa oli ohi. Eiväthän pelkät peräpukamat koko sielua saa myllerrykseen. <u>Puoli vuotta jatkunut hajaannustila, romahdus, lähestyvän maailmanlopun tunne, epätoivoinen masennus oli saanut vahvistuksen: Kasvain! Pyörähdin melkein iloisesti tutkimussängyltä ja nostin housut jalkaani. Helpotuksen tuntein varasin seuraavan poliklinikka-ajan.</u> He soittavat jos sitä ennen on jotain tiedotettavaa.</p>
[individual feelings and natural surroundings]	<p>[2] Kevyttä pakkaslunta leijui asfaltille, taivas oli sinien harmaa kun kävelin ulos kirurgisen sairaalan ovesta. Nyt elämä tuntui ainakin omalta. Olin ainakin joku. Minulla oli tapahtunut jotain, mitä ei kaikille tässä iässä tapahdu. Tunsin itseni liian nuoreksi ja samalla valmiiksi hautaan, 29 vuoden iässä. <u>Mikä voi olla syynä, että elämä, joka huolimatta vuosista, tuntui olevan vasta alullaan, voi jo nyt loppua. Mikä, niin mikä? En ymmärtänyt.</u> Kympin ratikka kaarsi pysäkillle. Vaunu, siinä istuva muutama ihminen, melko hiljaiset Helsingin kadut, viileä pakkasilma. Kaikki tuntui liian arkipäiväiseltä mutta samalla juhlavalta. Kuolemaa sisällään kantavan nuoren miehen tunnelma. Teki mieli kahvia ja viineriä.</p>
[pre-symptomatic health concerns]	<p>[3] Puoli vuotta tätä aikaisemmin työasiat rupesivat hermostuttamaan, reagoin koko ajan vatsallani. Joka päivästä piti selviytyä. Työ tuntui aina vaan järjettömämmältä. Tiesin että täällä olisi jotain tekemistä väsymisen ja masennuksen kanssa, mutta yleensä olin omassa tunteessa niin sisällä, että tarkoituksen puuttuminen ja suorituksesta selviäminen oli päivän sisältönä.</p>
[the smell of illness]	<p>[4] Eräänä yönä, nukkumaan käydessä, vaimoni, sanoi että käy suihkussa, sä haiset pahalle. Olin hikoillut, haistoin sen itse, hiki haisi suolistolle. Tämä on jotain, pelkoa, tiesin hien hajun muuttuvan elämän mukaan. Kävin suihkussa. Muistan sairastumiseen liittyvän hajun ja sen yön pimeyden.</p>
[pre-symptomatic health concerns]	<p>[5] Kamppailin siitä kevääseen. Stressaantuneena, kiukkuisena, helposti loukkaantuvana, odottaen kesälomaa. Kaikki tuntui olevan väärin, vallitsi olemassaolon heikkous. En pystynyt tekemällä muuttamaan mitään, ainakaan paremmaksi, tyytymättömyys ja syy hakeminen kaikkeen oli jokapäiväistä.</p> <p>[6] Odotin kesämökille pääsyä, lomaa. Siellä virkistyin. Olin joka kesä palauttanut talven tuhlatut voimat. Otin vielä ylimääräistä palkatonta vapaata, joka sopi erinomaisesti työn puolesta. Minulla oli pitkä kesä edessä, järven rannalla saunomisineen. Niittämistä, marjastamista, rauhaa ja luontoa, linnunlaulua sekä paljon pikkupuuhaa, tehdä niin kuin huvitti ja jaksoi. Tiesin, että syksyllä kaikki olisi toisin, mielialani kohentuisi. Linnut lauloivat, leppeä kesätuuli suhisi puissa, istuskelin huussin ovi auki nauttien luonnosta ja kesästä. Olin pannut merkille että täällä kävin liiankin usein. Tuntui kuin olisi tarve juosta yhtenään huussissa. ”Olisiko se tämä loma, lomaruuat, talven stressi”. Loppukesästä istuin huussissa jo hämmentyneenä. Suolisto ei asettunutkaan. ”Ottaapa se kauan. Vatsa on tullut vaan huonommaksi. No kaupungissa käyn lääkärissä, nyt on mätäkuu ja ehkä se siitä. Ainahan kaikki mene ohi jo se kerran tuleekin. Raitis ilma tekee joka tapauksessa hyvää. Etten vaan pelkää syksyä”, tuumailin.</p> <p>[7] Syksy oli lämmin. Kesä tuntui jatkuvan. Väsymys ei poistunut. Kävin vessassa yhtenään. Viimein olin pakotettu menemään terveyskeskukseen valittamaan, peräpukamista. Kerroin oireet ja lääkäri määräsi kylpyjä. Olin niin kuin pienessä kuumeessa, koko ajan tai vähän väliä.</p> <p>[8] En muista edes miten selviydyin töistäni. Siellä oli uusia ihmisiä töissä. Olin kuin vieras ja vanha työntekijä, joka ei oikein selviytynyt töistään. Olin huono. Minä joka olin mielestäni tehnyt paljon että olisin hyvä ja selviytyisin hienosti työn haasteista. Nyt olin siis tarmoton, hajamielinen, luonnevirkainenkin. En</p>

- saanut oikein mitään aikaan. Tämä asian tila ei nuorella ihmisellä näy ja hahmotu jonkin sairauden seurauksena. Kurjaa, tosi kurjaa. Sitten alkoi särky. Se paheni päivä päivältä. Jossain peräsuolen tienoilla ja jalassa, Jomotus, jota jatkui viikkokausia. Lääkärillä käyntejä. Peräpukamatko vain. (Kasvain painoi hermoa).
- [pain story] [9] Eräs kaunis syksyinen aamu jäi mieleeni, kävelin portista kadulle, aurinko paistoi lämpimästi, puiston puut loistivat keltaisina. Elämä ja olo oli hieno. Ei ollut olemassa mitään kovin näkyvää syytä onnen tunteeseen. Ratikassa huomasin, että jomotus oli ollut poissa. Muistin kun se palasi.
- [suffering alone] [10] Olin lyötynä ja nujerrettuna. Työ meni huonosti, vaimo alkoi hermostua olemiseeni. Ajattelin, että tämä nyt on varmaan jotain neuroosia vai mitä. K. tuli kotiin töistä eräänä päivänä. Olin jo saapunut muutamaa tuntia aikaisemmin, istunut ja ollut tuskissani. En tiennyt mitä tehdä. Lääkärille oli loppuviikosta aika. Täysi epätoivo ja fyysinen tuska oli vallannut mieleni. Istuin ja katsoin häntä. Huomasin kuinka hän säikähti, kun näki katseeni. Tiesin mikä katse se oli. Tuskan jäädyttämä armoa aneleva katse. Se sama kuin isälläni oli ollut muutamaa viikkoa ennen syöpään kuolemistaan. Kipu oli kovimmillaan, silti en halua vielä hyväksyä kuolemaa tosiasiana, mutta tietää sen olevan vääjäämättä tulossa. Minun siis oli piilotettava tuskani ja oltava niin kuin mitään suurta olisikaan meneillään. Menisin perjantaina lääkäriin ja olin valmis valittamaan perusteellisesti vaivoistani.
- [dream experience and interpretation] [11] ”Apua, räjähdys, minuun osui, kranaatinsirpale. Se oli repinyt vatsani, käsivarsi jomotti, oli pimeää. Missä olivat kaikki. Muistin, että makasin poterossa ja kranaatti oli repinyt vatsani. Olin lakanoissa. Olinko jo joukkosidontapaikassa”. Yövalo oli sängyn juuressa. Sotaa. Aamu valkeni sairaalassa. Potilassalissa nukuttiin vielä. Muistin olevani sairaalassa. Eilen minut leikattiin. Vatsan kohdalla oli kuin tyhjää. Kipulääkkeen huuma teki ajatukset selkeiksi, ruumis eli omaa elämää tippapullon varassa. Palautin mieleen eilistä. Sairaalan salissa oli varmaan yli kaksikymmentä potilasta, osa eilen leikattuja. Viikon vanhat katsellen meitä juuri operoituja sääliä ja ymmärrystä tuntien. He tiesivät mitä se oli ja mitä oli tulossa. Minulle tämä päivä oli kaikki. Olin jo maannut muutaman tunnin. Mistä mielikuva sodasta oli tullut. Toissapäivänä olin lukenut Seura-lehdestä kaupunginteatterin Tunteemattomasta sotilaasta, roolijaoista ja harjoituksista. Tämä oli minun yksityinen sotaani. Siihen siis joutuu ajasta riippumatta, jokaisen sukupolven vitsaus. Kaikki joutuvat määrittämän suhteensa elämän taisteluun henkilökohtaisella tasolla.
- [self-negotiation in hospital] [12] Makasin ja ajattelin, mitä antaisin että tätä päivää ei olisi; paljon paljon ja en mitään. Tämä hetki oli kaikki mitä minulla oli. Tästä jos en itse selviä, niin en mistään. Leikkaukseen menijöitä karrattiin ohitseni. Leikkausvaate päällä. Olin joutunut antamaan kehoni muiden käsiin. Kapealle leikkauspöydälle joutuminen pelkkä leikkausviitta yllä oli antautuminen, luovuttaa ruumiinsa toisten ammattitaidon käsiin. He tekivät työnsä, minä annoin koko elämäni. Minulla ei siinä vaiheessa ollut vaatimuksia. Luotin.
- [individual feelings and natural surroundings] [13] Hyvänolontunne itsessäni katsoin kirurgisen sairaalan salin puupylväitä. Niiden kauniit puuleikkaukset kaareutuivat taidokkaasti. Minkä painon nuo pylväät kannattivat. Koko rakennuksen paino suuressa harmoniassa painovoiman kanssa. Miten ihminen osaa. Huumattuna nautin tästä ihmistyön ihanuudesta. ”Että voi olla jotain näin nerokasta ja kaunista. Tuijottelin tätä ihmettä tuntikausia. Hoitaja tuli kyselemään miten täällä jaksellaan. Olin elämäni kunnossa. En ole kipeä enää ollenkaan. Kerralla kuntoon, voisin nyt lähteä tästä vaikka mihin. Näin hyvin kaikki oli siis käynyt. Hymyilin onnellisena. Olin siis parantunut päivässä kaikista vaivoistani, nukahdin.
- [14] Ystäväni olivat vuoteeni vieressä kun heräsin. Hyvin oli kaikki mennyt ja nyt vaan parannun.

[self-help]	[15] Seuraavan päivänä minun piti ottaa muutamia askelia. Tuntui kun vatsassani olisi rivi puukkoja. Haava parantuu, yritin ajatella. Oli fyysisen kivun vuoro. Tätä on puhdas kipu. Puukot vatsassa. En halunnut ottaa kipupiikkiä. Yritin pitkittää sen ottoa, tuntui kuin se auttaisi paranemista, mitä kauemmin pystyisi viiltelyä kestäämään, ennen kuin piikki turrutti ja sulki olon pumpuliinsa.
[religious experience]	[16] Oli pimeää, ulkona oli satanut, nyt oli sumu. Potilassali oli hiljainen. Varovasti hivuttauduin tippapullotelineen kanssa katsomaan ulos ikkunasta. Marraskuinen ilta Helsingissä. Vastapäisen talon seinällä oli joku valkoinen hahmo. Katsoin tarkemmin. Se oli Kristushahmo. Patsas joka siinä toivotti ikuista ja jatkuvaa siunausta kärsivälle ihmiskunnalle. En aikaisemmin ollut ajatellut uskontoa näin kouriintuntuvalle ja omakohtaisella tavalla. Mikä määrä tuskaa täällä oli itse kullakin lievitettävänä. Niin sinussa ja minussa, meissä kaikissa, ihmisissä, ystävissä kuin vihollisissa. Me kaikki olimme täällä. Jokin voima oli oltava ja jostain sitä li tultava. Vanhat eväät olivat minulta loppu. Sumu sai vaalean patsaan ympäristön säteilemään valoa. Se oli kuin ilmestys.
[life in hospital]	[17] Sairaalan mennessä olin ajatellut lukevani ja kirjoittavani päiväkirjaa, mutta ei siitä mitään tullut. Sairaus oli ja on kokopäiväinen työ. Ruoka, siivous, vessa, lääkkeet vuoron vaihto, päivä, yö, vierailut. Sitä se on, ennen kaikkea kotiin pääsyn odotusta.
[patient-doctor communication]	[18] Lääkärien kierros. Seurue vuoteen ympärillä, kaikki katsoivat minuun. Hoitava lääkäri jää selostamaan asiaani. He olivat poistaneet muutaman suspektin rauhasen samalla, tulokset tulevat loppuviikolla, jos niissä jotain ilmenee. ”Jaa jotain siis odotettavissa. Torstaina saa tietää”. [19] Perjantaina kysyin tuloksia, koska kukaan ei torstaina kertonut. Lääkäri lupasi tulla myöhemmin kertomaan tuloksista. Oli siis kerrottavaa. Tiesin. Olin valmis. Ottamaan elämältä vaikka kuoleman. Mentiin hoituhuoneeseen. Siellä oli vain yksi tuoli, lääkäri pyysi istumaan sängyn laidalle. Hän istu tuoliin, minua matalammalle. Muutaman vuoden minua vanhempi. Asia oli vaikea kertoa. ”Tässä työssä turtuu, näkee niin paljon, kaikilla on jotain”, hän aloitti. Näin että hän ei voinut olla samastumatta minuun. Tunsin myötätuntoa häntä kohtaan, arvostin työtä mitä hän teki. Tiesin että siitä sai kunnan korvauksen, mutta en olisi pystynyt itse tekemään lääkärin työtä mistään rahalla mitattavasta hinnasta. ”Niissä rauhaisissa oli löydökset”, hän sai sanottua. ”Mitä minun pitäisi tehdä ja seuraako mitään lisätoimenpiteitä, jälkihoitoja kyselin”. Tiesin etten halunnut enää mihinkään hoitoihin. Tämä leikkaus mielestäni oli jo riittävä, enempää en kestäisi. ”Tämän laatuiseen tuumoriin ei ole todettu sädehoidon vaikuttavan, joten seurataan aivan vain tilannetta, miten se kehittyy. ”Onko ravinnolla merkitystä”, kysyin. ”Leseitä voi syödä, niillä on jotain merkitystä”, totesi lääkäri neuvoakseen. Kiitin ja olin helpottunut. Ei enempää toimenpiteitä.
[evaluation: post-recovery time]	[20] Pilvet vaelsivat lännestä itään. Katselin poutapilviä, niiden auringon kuultamia reunuksia sinistä taivasta vasten. Pilvet muotoutuivat uudelleen, syntyi kasvot kunnes koko hahmo sai uuden muodon. Olin seurannut tätä kauan, ilman tuntumaa ajan kulumisesta. Lapsena muistin katselleeni pilvien kuviointia taivaalla. Olin samassa mielentilassa. Vaimoni pyysi kahville. Poutapäivä kesämökillä. Aikaa oli kulunut yli puoli vuotta leikkauksesta. Vaimoni sanoi, että ”sinähän olet oppinut olemaan, ennen ei olemisesta tullut mitään. Aina oli jotain puuhattava, korjattava, laitettava, koko ajan jotain”. Olin päättänyt elää vielä tämän kesän. ”Ensi kesä, vaikka, vaikka se olisi viimeinen, ajattelin silloin syksyllä, leikkauksen jälkeen. Nyt se oli tässä ja katsoin kärpistä ikkunassa. Ruoho oli vihreää.
	[21] Viime talvena, sairasloman jälkeen, työ ei maistunut. Muisti oli huono.

	<p>Leikkauksen ja vahvan nukutuksen seurausta, luulisin. Tutut ja työtoverit olivat järkyttyneet kuultuaan tapauksestani. Varmaan melkein haudanneet minut, päälle sepittäneet traagisen tarinan. Vaan elin ja tulin sairaslomalta töihin ja haukuin muita laiminlyönneistä, niistä, joita näin tapahtuneen poissa ollessani. Ennen olin ollut mielestäni liian kiltti, lupauduin ja en osannut sanoa ei. Jos sanoin, sanoin liian jyrkästi. Nyt päätin että se on loppu. Eli paskat välitin. Paljon hävittävää ei ollut. Seuraavan kesän olin päättänyt antaa itselleni, vapaana ja kesämökillä toipuen.</p>
[the meaning of cancer]	<p>[22] Kiirettä en kestänyt, se sai minut huonovointiseksi. Reagoin kuin olisin sille allerginen. Menetin pisteen, kiintokohdan, mistä käsin toimia, jos tuli kiire. Kyky elää kiireessä oli kadonnut, olin toipilas. Pako kiireeseen ei onnistunut, kuten ei vielääkään. Koin kiireen kuin synninteoksi, kulloisenkin tilanteen välttämiseksi, ohitukseksi. Panin merkille, että tuntemani kiireettömät ihmiset kuitenkin olivat aikaansaavia.</p>
[evaluation: post-recovery time]	<p>[23] Talven aikana mielessäni kiersi ajatus, miten elämä voi olla näin lyhyt, kolmekymmentä vuotta ei ole ihmisiässä juuri mitään. En ollut vielä päässyt kuin elämäni alkuun. Ajattelin että pitää tehdä tämä ja tämä ensin, ennen kuin voi tehdä sitä ja sitä, mitä todella aikoi. Ensin keskikoulu ja sitten vasta ylioppilaaksi. Nyt olivat päästötodistusta työntämässä käteen elämästä, vaikken tuntenut edes päässeeni kunnolla elämään sisään. Nyt pitäisi uskaltaa, toteuttaa mitä olin nuorena ajatellut. Haaveet tosiksi. olinhan mennyt töihin osittain siksi että teen töitä ensin ja sitten kun on varaa, niin toimin alkuperäisen suunnitelman mukaan. Aasi porkkanan perässä. Rohkeus että nyt tai ei koskaan, naputtelin sormen päällä työpöytäni reunaa, ikkunan takana oli roskapönttöjä ja teollisuustalon seinää. Tässä istui mies kohtalonsa kanssa. Loputtomiin odottelemisen ei enää onnistunut. Mutta ensi kesä ensiksi. Katson sitten jos olen hengissä, vuoden kuluttua tai silleen. Rohkeus, oliko mukana päättäväisyyttä, sopimus elämän kanssa, teen tämän ensin, sitten käyköön miten käy. Aloin kerätä rohkeutta mielen perukoilla. Menettämällä elämän saa sen. Voiko tappio olla voitto. Työhuoneeni katto roikkui palkeenkielinä kuin kuunmaisemana. Huomasin katselevani sitä pitkiä tovia ja annoin ajatusten tulla.</p>
[self-help]	<p>[24] ”Leseitä!” muistan lääkärin sanoneen: ”ne voi auttaa”. Lyhyt elämä, niin lyhyt ettei se selity millään tavoin. Näin lyhyessä ajassa en ole ollut valmis taivaaseen, vaikka mitkä synnit olisi anteeksi saanut. Enhän tiennyt, miten olin tänne tullut ja miksi olin sellainen kuin olin? Mitä olivat minun luonteen ominaisuudet, ajatukset, olinko pelkkä ympäristön tuote, kuka minä olin? Mikään ei selity pelkällä syntymällä ja kuolemalla. Jostain tultiin ja johonkin mentiin. Tämä tarina on pitempi, ei pelkkä alku ja loppu. Söin leseitä.</p>
[conclusion: the meaning of cancer]	<p>[25] Syövän ilmeneminen tapahtui noin viisitoista vuotta sitten. Se jälkeen on elämässä tapahtunut paljon. Yritys joka epäonnistui, avioero, opiskelu, ammatinvaihto, yksinäisyys, matkustelu, eläminen ulkomailla, työttömyys, jotkut lyhyet onnen hetket, kaikki se, mitä tähän elämään kuuluu. Missään suojatussa tilassa en tunne eläväni, jotta voin turvassa muistella ja ottaa välimatkaa elämän tosiasioihin, päinvastoin. Voin kuitenkin todeta, että sairastumiskokemus on vieläkin se arvokkain, joka minulla elämässäni on. Sain kokea jotain jo nuorena. Sain perspektiiviä ja syvyyttä jonka yleensä tulee vasta myöhemmin. Selvästi on todettavissa, että syöpä on parasta ja pahinta mitä tähänastisessa elämässäni on tapahtunut. Arvokkain kokemukseni.</p>

Regarding the structural segments, I have divided Seth's story into 25 episodes. His writing concentrates on four temporally and spatially defined meeting points: the moment of diagnosis, the half-year before the diagnosis, the time after the surgery spent in the



hospital, and the half-year after the surgery. His conclusions indicate the meaning of cancer from a distance of 15 years. In the first episode [1] Seth describes how his carcinoma was discovered. The diagnosis comes as a relief to him because he suffered for a long time before the cause of his illness was discovered. After describing his primary feelings after diagnosis [2], he moves back in time and describes how his health concerns came to influence his daily life [3, 4, 5, 6]. Particularly meaningful in his story is the moment when his wife tells him that he should shower, because he smells bad [4]. From this moment on, the smell of intestines becomes memorised as the smell of his illness.

Seth's reasoning during the half-year before going to visit the physician is in many ways similar to ideas presented in numerous cancer narratives. Namely that people suffering from the long winter and work pressures seem to live in hope that in spring, or at least during the summer vacation, everything will be fine again and that a good feeling about one's condition will return. However, as the expected recovery does not take place, Seth decides to visit his doctor when he returns to the city. The first diagnosis, haemorrhoids, as well as the treatments given, are wrong [7]. Meanwhile Seth's condition gets worse [8]. He suffers from pain and occasional fever. The pain gains control over his daily life. One day he enjoys the beautiful autumn surrounding him. He is happy as he notices that the pain has left him; as it returns he feels devastated [9]. He looks at his wife in his pain and desperation and the situation reminds him of his father, who died of cancer. Thus, Seth reaches a decision. No matter what, doctors have to find out the reason for his terrible condition, until then he must suffer alone [10].

The story's events continue after the surgery, first with descriptions of time spent in the healthcare institution. The day after the surgery begins with a dream of him being wounded in the war. As he wakes up, he interprets his dream as an individual war that he must survive at any cost [11]. The following day, in order to get better, he gives up his painkillers and decides to entrust his body to the physicians [12, 13, 14, 15]. One night, when looking out of the window, Seth notices the figure of Jesus. He realises that he needs the external power of religion as he himself is totally empty [16]. Life in hospital is full of routines, so he has no time to read or write as he had planned. Seth waits to go home [17]. As the doctors visit his bed, he understands that there is more on the way. He comes to the conclusion that he has to accept it, even if it is his death sentence. The doctor promises to come on Thursday, on Friday he looks up the doctor himself. Seth gets the feeling that the doctor, who is few years older than he, does not know how to handle the situation. What

should one say? Seth asks about his condition, he finds out that he has cancer and that there are no biomedical treatments available that would help him further. He is satisfied, but asks if eating bran would help him. The doctor says that this might have some significance [18, 19].

Half a year after the surgery Seth is again in his summer cottage. He is thinking about his life after he returned to work [20]. His colleagues were shocked, and he thinks that they had buried him alive. He had realised that he cannot continue living in a hurry like his colleagues. He makes plans to change his life if he survives the summer [21, 22, 23]; meanwhile, he eats bran [24]. Throughout his story Seth describes his feelings and thoughts at the time of the events. Only in the final episode, which may be described as the evaluation of his cancer experience, does he express his current thoughts regarding the significance of his past experience. Fifteen years later he admits that cancer has been the most valuable experience in his life [25].

## **Hanna's story: *Mitä ajattelinkaan ennen kuin sairastuin syöpään?* (What did I think before I fell ill with cancer?)**

The second cancer narrative selected for detailed analysis begins with a covering letter in which the respondent, Hanna, explains that work pressures were the cause of the delay in sending her story: *“Lähetän kirjoitukseni työkiireiden vuoksi näin myöhään – toivottavasti siitä on apua valitessanne materiaalia kirjaan. Muistutan, että haluan käyttää nimimerkkiä, jos julkaisette tekstin. Onko nimimerkki liian pitkä?”* In her covering letter, Hanna also reiterates that she wants to use a nickname if the story is selected for publishing.

[The time before the diagnosis]

[1] Tasan seitsemän vuotta sitten oli 30:s syntymäpäiväni. Päivä oli sateisista sateisin, keittiössä kaksi ikäistäni naapurin äitiä odotti juhlahahveja ja lattialla kolme puolivuotiasta vauvaa yritti seurustella keskenään – oma tyttäreni oli kättyisä ja väsynyt niin kuin minäkin. Olin juuri tilannut ajan tutulle gynekologille ja mietin yhä, oliko mitään järkeä lähteä niin epämääräisen tuntemuksen takia lääkärille. Toivoin vain, että naapurit joisivat kahvit nopeasti tai vauvat nostaisivat sellaisen kohtauksen, että pääsisin vieraista eroon ja miettimään asioitani rauhassa.

[Pre-symptomatic health concerns]

[2] Olin jo pari kuukautta synnytyksen jälkeen tuntenut möykyn alavatsassa. Synnytyksen jälkitarkastuksessa gynekologi totesi, että kohtu ei ole supistunut hyvin ja antoi siihen lääkekuurin. Tämä tieto riitti minulle kesän ajan. Loppukesästä sisareni kysyi, odotanko jo uutta lasta. Loukkaannuin hieman ja totesin, että olen entisissä mittoissani, painokin on itse asiassa laskenut alle raskautta edeltävien aikojen. Vähän myöhemmin huomasin, etten pysty olemaan

	<p>vatsallani lattialla kun leikin lapsen kanssa – jouduin pitämään peffaa hieman koholla ja kallistumaan oikealle, jokin painoi vatsanpohjaa. Miehenikin tunsikin kämmenellä painaessaan, että vatsa oli hieman toispuoleinen. Näillä tiedoilla tilasin ajan lääkärille. Kerroin myös olevani kuolemanväsytynyt, valitsin sattumalta oikean sanan kuvamaan vointiani. Aina kun mahdollista kävin nukkumaan, vaivuinkin pohjattoman tuntuiseen uneen, josta en olisi jaksanut millään herätä. Arvelin lääkärille, että varmaankin se johtuu lapsenhoidosta, vaikka tytär olikin kiltti ja antoi nukkua yöt ja puoliso auttoi kaikessa mahdollisessa.</p>
[The moment of diagnosis]	<p>[3] Viikkoa myöhemmin olin yksityisvastaanotolla. Kun sisätutkimus alkoi, lääkäri kirjaimellisesti kalpeni: ”Oikea puoli terve... mutta... vasemmalla on munasarjakasvain! se kiertyy tänne kohdun alle.” Pitkäaikaisen gynekologini reaktion ymmärsin – hänen varsinainen päivätyönsä oli syöpäsairaalassa. Seuraavana päivänä tehty ultraäänitutkimukseen ei tuonut selvyyttä kasvaimen laatuun; yhteinen toteamus oli, että kasvain oli suuri eikä ainakaan syöpää. Sain kuitenkin lähetteen kiireiseen leikkaukseen. Lisätutkimukset eivät tuoneet uutta tietoa, kasvaimen rakenne säilyi tuntemattomana. Lääkäreille totuus valkeni vasta leikkaussalissa ja minulle vuorokausi myöhemmin, kun oli riittävästi herännyt pitkästä narkoosista ja kipupiikeistä.</p>
[Patient-doctor communication, the moment of diagnosis]	<p>[4] Naiskirurgi piti kättä polvellani, katseli hieman ohitseni ja kertoi lyhykäisesti, että kasvain oli tutkittua vieläkin suurempi, että se oli kuitenkin syöpäkasvain ja kohtu ja munasarjat oli jouduttu poistamaan, koska pahanlaatuinen solumuutos oli löytynyt myös oikealta puolelta. Kirurgi totesi, että kaikki oli saatu poistetuksi eikä kasvain ollut kiinnittynyt mihinkään, vaikka sen koko olikin 15x20 senttiä – siis lähes vastasyntyneen päähän verrattava! Lääkäri tajusi olla hiljaa, jotta sain aikaa yrittää ymmärtää; ”<u>Nyt se on sitten minussa</u>”, oli ensimmäinen ajatukseni.</p>
[The meaning of the illness]	<p>[5] En ollut sillä hetkellä enkä ole koskaan myöhemminkään ollut sairastumisestani katkera. En ole koskaan kysellyt itseltäni, miksi juuri minä sairastun. Jos olisin ajatellut niin, olisin siis samalla toivonut, että joku muu olisi ollut minun sijassani. Olin tyytyväinen, kun löysin tämä humanin puolen itsessäni.</p>
[Talking about cancer to her husband]	<p>[6] Pyysin lääkäriä soittamaan mieheni paikalle ja sain itse kertoa hänelle asian. Tilanne oli unenomainen; iloinen vauva heräili kantokassissa, mieheni itki polvillaan sängyn vieressä ja yritti olla painamatta letkuja, jotka risteilivät pitkin sänkyä ja telineitä, minä olin lääkkeitä turvoksissa ja sekava ja vakuutin, että leikkaus oli onnistunut. Tosin samaan hengenvetoon jouduin sanomaan, että sytostaattihoito alkaa pian eikä asioita kannata suunnitella kovin pitkälle. Mieheni kertoi myöhemmin, että hän oli kotiin tultuaan siivonnut kaksi päivää ja itkenyt suureen ääneen silloin, kun imurin ääni peitti kaiken muun.</p>
[The treatment]	<p>[7] Elämässämme alkoi se kaikille syöpäpotilaille tuttu epävarmuuden aika, joka ei koskaan täysin pääty. Olin äärimmäisen heikossa kunnossa. Lapsen syntymän jälkeen munasarjasyöpä oli kehittynyt huikealla vauhdilla ja kuluttanut energiaani. En ollut päässyt toipumaan synnytyksestä, imetys oli vaatinut osansa ja nyt pelko tulevasta kuristi meitä molempia.</p>
[Talking about cancer to others]	<p>[8] Kerroin sairaudestani van sisaruksille ja eräille läheisille. Kielsin heitä jatkamasta juttua, mutta vahinko oli jo tapahtunut. Veljeni vaimo ei ollut toivottani kuullut, ja niinpä hän ehti kertoa kuulumiseni sukulasirouvalle pikkukaupungin kadunkulmassa jo silloin, kun minä vielä makasin sairaalassa! Se oli minulle suuri järkytys ja loukkaus. Tämä tapahtuma oli sairaalassa suurin murheeni. Raivoistuinkin siitä, että asia, jota en edes itse ymmärtänyt, oli jo yleisen päivittelyn kohde. Sain sukulaisten suut suljetuiksi yhdellä kirjeellä ja vihaisella soitolla veljen vaimolle. Sen jälkeen hän ei ole kysynyt vointiani.</p>
[The significance of social support]	<p>[9] Sairastuminen osui vuosiin, jolloin valtio vielä tuki runsain mitoin lapsiperheitä. Sairaalassa käyntipäiväksi onnistuin saamaan aina saman</p>

kodinhoitajan – asia, joka helpotti suunnattomasti oloani. Suurin apu koko pienelle perheellemme oli kuitenkin lapsen kummi, opiskelukaverini, joka jättäytyi syksyksi töistään pois hoitaakseen minua ja lasta! Hän asui meillä, hoidimme yhdessä kotiasiat ja sain levätä ja ulkoilla vointini mukaan. Miehelläni järjestely oli myös oivallinen, koska työnsä puolesta hän joutui matkustelemaan ja tekemään pitkiäkin päiviä. Olen vuosi vuodeltaan vakuuttuneempi siitä, että läheisen apu noina ensimmäisinä kuukausina pelasti paljon ja säästi perhettämme monelta myöhäisemmältä tuskalta. Saimme molemmat surra ja kerätä voimia ilman jokahetkistä huolta vauvan hoidosta ja ruuanlaitosta. Elämän käytännön järjestelythän kuluttavat ihmisiä joskus enemmän kuin sairaus. Ystävämme on myös poikkeuksellisen iloinen ja aidosti tunteva ihminen, joten hänen seuransa toi väriä ja uusia ajatuksia muuten niin sulkeutuneeseen kotiimme. Emme kaivanneet muita.

[Self-help]

[10] Noudatin tiivistä lääkärin ohjetta runsaasta ulkoilusta. Työnsin lastenvaunuja pitkin sumuisia ja sateisia ulkoilualueita ja yritin ymmärtää, mitä käytännössä tarkoitti lääkärin neuvo olla suunnittelematta asioita pitkiksi ajoiksi eteenpäin. Ohjeena oli ainoastaan kerätä voimia seuraavaa hoitokertaa varten. Oli tietysti hyvä, että lääkärit eivät alussa luvanneet paranemista, koska eiväthän hekään tulleet hoidon onnistumisesta.

[Thoughts about dying and death]

[11] Koko syksyn järjestelin ajatuksissani hautajaisiani. Etenkin ulkoillessani laadin erilaisia kuolinilmoituksia ja muistotilaisuuksia. Mietin, kuinka työkaverit järkyttyisivät, kun saisivat yhtäkkiä viestin kuolemastani. Itkin omille ajatuksilleni, mutta onneksi päivät olivat niin harmaita, etteivät vastaantulijat kiinnittäneet huomiota punaiseen nenääni. Tunnustelin vaihtoehtoja, keille voisin kertoa sairaudestani, mutta työpaikalta en kelpuuttanut joukkoon ketään. En halunnut silloin enkä halua nytkään, että työtoverit tarkkailisivat vointiani ja kyselisivät, luultavasti mitä kummallisimmissa tilanteissa, taudinkuvaani. Tällaiset mietiskelyt – itsesäätilenkit tekivät tehtävänsä – olin niiden jälkeen kyllästynyt joksikin aikaa aiheeseen, sopivasti nälkäinen ja väsynyt, joten muutama tunti kului taas tarkoituksenmukaisesti eteenpäin.

[Biomedical treatments and self-help]

[12] Minua lääkittiin neljän viikon välein solunsalpaajilla, kuuri kesti puoli vuotta ja sitten oli vuorossa vielä second look-leikkaus. Kahdeksan kuukauden sairasloman jälkeen painoin 49 kiloa, painoa oli häipynyt kuusi kiloa. Näytin kuivettuneelta luukasalta – joskus tunsin itseni keskitysleirivangiksi. Minun on turha kuvata pahoinvointejani ja tutkimuksia – jokainen sairaalassa ollut tietää ne ja uusia potilaita on turha säilytellä. Mistä hyvänsä sairaudesta paraneminen ja kunnan ylläpito perustuvat pitkälti omaan tahtoon. Tein mielessäni selvän jaon – lääkärit hoitavat oman osuutensa ja minä omani; esimerkiksi jos en olisi hoitojen välillä pakottanut itseäni syömään terveellisesti, en olisi heikkojen veriarvojen vuoksi voinut ottaa sytostaatteja ja hoito olisi keskeytynyt. Loogista, mutta niin raskasta! En silti halunnut heittäytyä täysin avuttomaksi, koska näin monia huonommassa kunnossa olevia ja hekin jaksoivat. En tietenkään usko, että olin pelkällä tahdonvoimalla estänyt syöpää leviämästä, mutta varmasti pystyin vaikuttamaan toipumiseeni.

[13] Niin kuin jo kirjoitin, sain kaipaamani huomion ja yksityisyyden perheen piirissä. Se ratkaisu sopi minulle, joku toinen kaipaava laajaa piiriä ympärilleen. Sairaalassakin huomattiin tämä järjestely, ja ilmeisesti siksi minulta ei missään vaiheessa tarkkaan kysytty olenko jokinlaisen käytännön avun tarpeessa. Enemmän kuin senhetkisen avun tarjoamista, odotin keskusteluja avio- ja sukupuolielämästä ja niistä mahdollisesti ilmenevistä ongelmista. Raskauden, synnytyksen ja sairastumisen takia olimme käytännössä runsaan vuoden ilman sukupuolielämää. Kolmekymppisenä minulla ei ollut enää kuukautisia, jäljellä oli vain emätin, ja söin pillerin verran estrogeenia päivittäin estääkseni vaihdevuosisioireet. Vasta hoidon ja sairasloman päätyttyä tajusin, ettei kukaan ollut antanut edes minkäänlaista asiantuntijamonistetta luettavaksi, jossa olisi

- kerrottu näin radikaalin leikkauksen vaikutuksesta (nuoren) naisen elämään. Sellaista ei ilmeisesti ollut olemassa. Koska minulle ei ilmaantunut mitään ylitsepääsemättömiä vaikeuksia, en enää välittänyt palata asiaan tarkastuskäyntienkään yhteydessä. Nopea käynti syöpäpoliklinikan jatkuvasti vaihtuvilla lääkäreillä ei oikeastaan anna tällaiseen keskusteluun mahdollisuuttakaan.
- [Patient-doctor communication, the need for psychological support] [14] Missään vaiheessa kukaan ei myöskään kysynyt, kuinka suuri isku meille oli, ettemme saisi enää toista lasta. Minulla oli aiemmin ollut yksi keskenmeno, ja nyt teimme jo uudenlaista surutyötä, murehdimme menetettyjä mahdollisuuksia. Minusta hoitajien, ja etenkin Naistenklinikan omahoitajan, olisi pitänyt ottaa nämä asiat esille, kun kerran itse en osannut sitä tehdä. Lyhytkin keskustelu olisi auttanut järjestämään ajatuksia ja olisi antanut pohjia asian käsittelylle kotona. Muistan, kuinka tärkeää miehelleni oli kuulla sanasta sanaan, mitä lääkärit ja hoitajat olivat minulla puhuneet.
- [Returning to work] [15] Alle vuoden kestäneen intensiivisen hoidon jälkeen parannuin. Palasin työhön, jossa kukaan ei voinut muistuttaa asiasta, koska he luulivat minun olleen äitiysloman jatkoksi lastenhoitovapaalla. Sairastumisesta alkaen pohdin noin puolentoista vuoden verran KOKO AJAN vointiani – ainut hetki, jolloin unohdin tautini oli silloin, kun hoidin lastani. Ihmettelin, pystynkö koskaan siirtämään sairauttani sivuun. Työnteko alkoi kuitenkin täyttää ajatuksia niin, että muutakin mietittävää löytyi.
- [The significance of cancer] [16] Vieläkään ei ole kulunut (ja tuskinpa tule kulumaankaan) päivää, ettei syöpä olisi mielessäni. Se ei mielestäni kuitenkaan vaikuta toimintaani. En ole henkisesti rasittunut, en näe painajaisia enkä pelkää uudelleen sairastumista. Tiedän kuitenkin, että kypsyttelen itseäni siihen hetkeen, jolloin tauti mahdollisesti uusiutuu. Voisin mukaella tähän vanhaa Flora-mainosta: ”Mitä ajattelinkaan ennen kuin sairastuin syöpään?”
- [Concerns about her child’s future] [17] Olen myös alkanut valmistella lastani tottumaan tämännimiseen sairauteen. Se on tapahtunut osin huomaamatta. Olen varovaisesti kertonut syöpää sairastavista ystäväistäni ja eräästä siihen menehtyneestä. Samalla olen selvittänyt, että oma elämäntapa vaikuttaa paljon, mutta sairaaloissa autetaan kaikkia. Pikku tyttäreni kaipaa kovasti sisarusta, mutta hän on tyytynyt selitykseen, kun kerron, että minulla on ollut niin kipeä vasta, ettei uusi vauva pääse kasvamaan. Kerron kaiken sitten, kun hänen käsityskykynsä riittää, eivätkä pelot saa yliotetta.
- [The importance of taking care of oneself] [18] Elämä on tasaantunut, avioelämä on kehittynyt hauskaksi ja fyysinen vointi tuntuu yhä paranevan. Kunnon ja tuntemuksien tarkkailussa olen kehittynyt ehkä jopa liikaakin, kauan en oireitani yksin kuuntele. Mutta kukapa minut tutkimuksiin lähettäisi, ellen itse menisi lääkärielle?
- [Concern about the future] [19] Kesän aikana olen kärsinyt vatsakivuista ja kolmesta nopeasta kuumepiikistä – tulokset tulevat huomenna. Tässä vaiheessa tuttu pelko kouraisee mieltä... toivottavasti se on huomenna tähän aikaan ohi.

In a similarly way to Seth’s story, Hanna’s story also describes the discovery of her tumour in the opening part. Describing her pre-diagnosis health concerns, she moves back in time creating the setting for the forthcoming events, the surgery, and treatment received in hospital. In Hanna’s case her body is overwhelmed by constant tiredness. As she is the mother of a six-month-old baby, she connects her tiredness with her role as a mother, although the baby is very calm and she shares her parental duties with her husband [1]. A

lump in her stomach, which she can feel and others can see, tells of her abnormal condition [2].

When her gynaecologist discovers the carcinoma, Hanna does not know what kind of growth it is. This becomes clear when she wakes up after the surgery [3]. Despite the structural similarity, compared to Seth's story Hanna's writing contains more evaluation. From the sixth episode onwards Hanna describes and evaluates events, comparing her primary feelings to her later thoughts and ideas. The evaluative quality of Hanna's story allows the suggestion that, particularly in the final part of her story, she has tried to answer the questions posed by the organisers of the writing competition. Thus, the moment she hears her diagnosis is described from an evaluative point of view. Hanna is not bitter that she has got "IT" [5]. Instead, she describes her husband's devastation as she tells him not to make any long-term plans [6]. For Hanna and her family, uncertain times, as Hanna puts it, which have no end because of the cancer, begin [7, 17, 19]. Like Seth, Hanna also keeps quiet about her illness. She decides to talk about her condition only to her closest relatives. She is very annoyed when she understands that her sister-in-law has not kept quiet as she desired [8].

Hanna describes the importance of social support and the help she received from her family and friends. She also stresses the importance of self-help in order to become well [10, 18]. Long walks with the baby in the pram were times when she could deal with her inner struggles, think about her lethal disease, plan her own funeral and think about work colleagues' reactions. Hanna received cytostatic treatments over a period of half a year. She lost weight and suffered, but she says that she did not want to discuss it, as those who have experienced such treatments know how it feels, and she did not want to scare new patients [12]. Concerning the help received in the health care institutions, she is sad that no one told her about the possibility to continue her sex life after her operation [13]. In Hanna's words she and her husband were missing some advice and help, as due to surgery she was infertile and they would have to face the prospect of not having more children [14].

Hanna went back to work after the treatments. Her colleagues did not know about her illness and thought that she was enjoying extended maternity leave. Thus, she was saved from questions about her health condition in unexpected situations [16]. Six years afterwards Hanna's life has moved on. She has developed a good understanding and physical relationship with her husband without any help from outside [18]. She also says

that she has begun to prepare her daughter with the idea that people die of cancer [17]. This fact points out her continued fear about her remission, which makes her visit the doctor every time she feels something unexpected in her body [19].

## Ruth's story: *Melanooma ja minä* (Melanoma and I)

[The meaning of cancer, cancer aetiology]

[1] Kun kuulen sanan melanooma, tuntuu kun kuolemantuomio olisi julistettu, ”mutta se koska tuomio pannaan täytäntöön siitä ei ole tarkkaa tietoa”. Näin ainakin minusta on tuntunut. En tiedä, miten muut sen kokevat. Ehkäpä oma pelkoni, juuri tätä syöpämuotoa kohtaan juontaa opiskeluajoilta. Opiskellessani sairaanhoitajaksi meille pidettiin laaja luento melanoomasta. Sen eri muodoista ja luokituksista ja siitä miten huono ennuste sillä on. Niinpä siinä kävi että pelkoni toteutui – aloin miettiä – että onkohan näin, mitä eniten pelkää sen kohtaat elämässäsi. Voisiko puhua Karman laista – eli ajatukset vaikuttavat kohtaloon.

[Individual lifestory]

[2] Oli juhannuksen jälkeinen ensimmäinen arkipäivä 1992. Puhelin soi, menin iloisesti vastamaan, olin todella hyvällä tuulella. Olinhan viettänyt ihanan kesäloman ja olin rakastunut ja lomaa oli vielä jäljellä, kaikki tuntui niin uskomattoman hyvältä – vaikka minulle ennen lomaa tapahtui keskenmeno – jota en olisi halunnut tapahtuvan. Olinhan yrittänyt lasta kymmenen vuotta ja nyt kun tulin raskaaksi niin se oli minusta ihme. Mutta menetin sen ihmeen ja se koski.

[The moment of diagnosis]

Ennestään minulla on yksi aikuinen poika, poika joka tallaa omia polkujaan. Siksi, pieni tuoksuva kääre olisi ollut taivaan lahja. Kohtuuni jäi vaan iso myooma, joka oli myös keskenmenon aiheuttaja. Edessä ei ollut muuta mahdollisuutta, kuin kohdun poisto. Jäin odottelemaan koska sairaalasta tulee ilmoitus kyseistä leikkausta varten.

Niin, olin menossa vastaamaan puhelimeen. Nostin reippaasti luurin, luurin toisessa päässä oli työterveyslääkäri. Tajusin hetkessä mistä oli kyse. Tunsin huimausta. Ymmärsin siinä samassa, että se mitättömän näköinen luomi on osoittautunutkin pahanlaatuiseksi.

Työterveyslääkäri luurin toisessa päässä alkoi kertomaan hyvin rauhallisella äänellä; että oikean jalan pohkeesta poistettu rupimainen luomi on osoittautunut pahanlaatuiseksi melanoomaksi. Olin yksin kotona. Lyyhistyin lattialle, kuulin kun hän jatkoi: Kirjotaan teille läheteen keskussairaalaan, sieltä tulee kutsu noin kahden viikon sisällä. Ja lääkäri jatkoi: jalkaanne tullaan tekemään ihonsiirto, koska yleensä joudutaan poistamaan runsaasti kudosta kyseiseltä alueelta ja ehkä vielä jatkohoitona joudutaan antamaan sädehoitoa. Kuuntelin lääkärin puhetta aivan sanattomana ja totesin: olen täysin pöllähtänyt, se oli ainoa mitä sen puhelinkeskustelun aikana sain sanotuksi. Lääkäri ymmärsi täysin – tai ainakin oletin – miltä minusta tuntui. Suljin luurin. Elämäni täytti tyhjiys. Tunsin kuolevani siihen paikkaan, tai oikeastaan ajattelin, että enhän voi kuolla, koska olen täysin terve, onnellinen ja niin elinvoimainen. Kielsin koko asian. Todellisuudessa aloin heti tekemään surutyötä. Minulle tuli kaamea kaaosmainen tunne, etten pystynyt edes itkemään. Hetkessä suunnittelin omat hautajaiseni. Ettei pojalle jäisi mitään järjestettävää ja näin ollen hänelle ei tulisi mitään ylimääräisiä menoja. Koska hän on ollut pitkään työttömänä ja en vuoksi elämä luisunut pois raiteilta eli kaljoittelu saanut ylivallan. Entä nyt, kun hän saa tietää että minulla on syöpä, tuleeko hänestä täysin alkoholisti vai

lopettaako ryypäämisen. Sanotaanhan ”että ihminen sairastumalla kontrolloi ympäristöä.”

Niin, mietin – miten kerron pojalleni. Hän on jo menettänyt kaikki rakkaimpansa, viimeksi oman isänsä keväällä pari vuotta sitten. Poikani – joka on suuremman osa elämästään viettänyt synkkää lapsuutta. Koulussa kiusattu – potkittu mustelmille, rahaa kiristetty, kokenut avioeron kriisit ja vaikka mitä. Nyt tämä. Voi hyvä luoja, rukoilin Jumalalta voimia. Ja miten kerron miesystävälleni? Hänen veljensä on kuollut melanoomaan. Keväällä kun tapasin tämän nykyisen miesystäväni, niin hän ensimmäisenä kertoi minulla veljestään. Veli joka eli vain puoli vuotta siitä un melanooma hänellä todettiin. Se oli ollut mies ystävälleni kova paikka, koska hänen veljensä oli vasta 38-vuotias, aviossa pieniä lapsia, asunto velkaa ja miten kaikilta elämä romahti melanooman takia. Nyt tästä tapauksesta on kulunut yli neljä vuotta, niin vieläkin se häntä koskettaa. Silloin mietin, pala kurkussa, miten hänelle kerron, että minullakin on melanooma. Entä minun sisareni. Miten heille kertoisin? Meiltä on jo kuollut yksi sisko syöpään, mutta siitä on aikaa. Siskoni oli kymmenenvuotias kun hän kuoli, itse olin silloin kahdeksanvuotias.

Oli tunti kulunut siitä tiedosta että minulla on melanooma ja olin mielessäni käynyt läpi hirvittävästi asioita. Minulle tuli aivan paniikki, tuntui etten pysty hengittämään. Suurin ahdistava tunne tuli lähiomaisista. Minullehan se on helppoa kun kuolen, mutta ne jotka jäävät tänne – aloin itkeä – en tiedä, itkinkö lähiomaisten puolesta – vaan itseni. Minun kaksi kissaa katsoivat silmät pyöreinä kun istuin lattialla ja itkin.

[Cancer aetiology] [3] Katsoin ikkunan suuntaan näin auringon paistavan, kesä oli kauneimmillaan – yks, kaks vihasin aurinkoa jota ennen niin rakastin, nyt tunsin sen vihollisekseni. Vaikka ajattelin hyvin sekaisin tuntein, ettei melanooma voi olla pelkästään auringon aiheuttama. Sairastumisalttiutta on voinut lisätä perimä – entä virukset – sillä herkästi saan suunlimakalvolla herpesen ja jalkaan ruusun. Oli nyt aiheuttaja mikä tahansa, sillä totuus on vain se, että minulla on melanooma.

[Talking about cancer to others] [4] Jäin odottelemaan, koska tulee kutsu leikkaukseen. Hirvittävä pelko täytti sisimpäni. Kutsu sairaalaan tuli melko pian. Sinä aikana, kun odotin sairaalaan pääsyä, eli se kaksi viikkoa, oli elämäni kauheinta aikaa. En voinut kertoa pojalleni – en miesystävälleni – en kellekään – mikä minulla oli. Muutuin erittäin aggressiiviseksi. Ajattelin: että kun olen oikein inhottava, niin kukaan ei ikävöi minua kun kuolen. Käytöstäni ihmeteltiin. Kunnes heinäkuun 11 päivänä kerroin, että minun jalastani poistettu luomi oli pahanlaatuinen ja että huomenna menen sairaalaan. En voinut kertoa, että se oli melanooma. Ehkäpä pojalleni melanooma ei olisi sanonut vielä mitään – mutta miesystäväni – reagointia pelkäsin.

[Suffering alone] [5] Jätin asian ilmaan roikkumaan. Oli [---] päivä, menin keskussairaalaan kirurgian osastolle. Minut otettiin ystävällisesti vastaan. Osastonlääkäri tuli tekemään haastattelua. Kyseli, onko suvussa ollut syöpää, olenko ollut kova ottamaan aurinkoa, onko hiusteni väri oma, eli punaiset jne... Kaikkiin oli vastattava myönteisesti. Minulle näytettiin vuoteeni, istuin sen reunalla ”se oli kuin laiva, joka oli uppoamaisillaan”. Jäin siihen odottelemaan, toimenpiteeseen osallistuvia lääkäreitä. Anestesia lääkäri oli keski-ikäinen nainen, erittäin ystävällinen. Hän otti tuolin vuoteeni viereen, istui siihen ja kertoi rauhallisesti spinaalianestesiasta. Sitten tuli tyypillinen kirurgi luokseni. Hän seisoi vuoteeni vieressä karvaiset kädet puuskassa. Iältään noin nelikymppinen, tumma, hieman lyhyehkö aika hauskan näköinen. Asiallisesti selittäen hän kertoi miten leikkaus suoritetaan. Eli poistetaan kudosta laajalta alueelta a syvältä, reidestä siirretään ihoa leikkausalueelle. Sitten hän oli pahoillaan, kun jalkaan tulee jäämään syvä kuoppa. – No sekös



	minua enää siinä vaiheessa harmitti.
[Talking to her son and husband]	[6] Lääkäreitten käyntien jälkeen, minulle jäi loppoaikaa. Tuli kauhea koti-ikävä, minun oli pakko päästä kotiin. Ja niin sovimme osastolla, että voin mennä yöksi kotiin ja tulla sitten aamulla. Sain hoitajalta ohjeet miten teen esivalmistelut illalla, sekä unilääkkeen jonka voin ottaa tarvittaessa. Olin kotona aivan kuin viimeistä kertaa. Mielessäni hyvästeli poikani, ystäväni ja kissani. Soitin sisarelleeni ja kerroin mikä oli tilanne, kuitenkin asiaa vähätellen – vaikka sisimmässäni itkin. Olin jo tavallaan antanut periksi ja hyväksynyt kohtaloni. Tuntui, että ympärillä olevat ihmisetkin sen hyväksyivät, eli poikani ja miesystäväni, koska eivät halunneet asiasta puhua. Sen he totesivat, että ilmankos olet ollut niin outo, masentunut ja hyvin kireä. Myönsin sen kaiken johtuvan siitä, etten tiennyt, miten tästä kertoisin. – <u>Tajusin, miten kätkeyty suru voi vahingoittaa ympäristöä.</u> Yön nukuin hyvin, osittain unilääkkeen ansiosta, osittain siksi että olin edellisen yön valvonut ja siksi että aloin hyväksyä asian.
[In the hospital, patient-doctor communication]	[7] Lähdin aamulla varhain osastolle. Minusta tuntui kuin olisin mennyt suonikohjuleikkaukseen. Sain avopaidan, menin suihkuun, sain esilääkityksen ja sen jälkeen ei saanut nousta vuoteesta – jäin odottelemaan, vuoroani. Ei tarvinnut kauaa odotella, kun nuori vaalea hoitaja tuli vuoteeni viereen. Kädessään hänellä oli paperini joita hän vilkaisi ja totesi, nyt voimmekin lähteä. Matka leikkaussaliin tuntui pitkältä. Minut siirrettiin leikkauspöydälle. Sain selkäydin puudutuksen, hetken kuluttua jalat tuntui raskaalta lyijyiltä ja aivan kuin ne olisivat olleet jäässä. Jalkani, mistä ”luomi” melanooma oli löytynyt nostettiin leikkaustelineelle. Tuntui mystilliseltä, kun näin oman jalkani (kunnes se peitettiin vihreällä leikkausliinalla) mutta en tuntenut mitään. Leikkaussalissa oli radio auki, keskityin kuuntelemaan sitä ja samalla vaihdoin muutaman sanan anestesia-hoitajan kanssa.
[Surgery]	[8] Olin leikkauksessa noin 45 min. sitten minut siirrettiin osastolle. Huomasin että ihonsiirtoa ei ollut tehty – en oikein ymmärtänyt miten leikkaus oli suoritettu. Ja koska leikattu jalka oli hyvin sidoksilla peitetty, niin jäin vain odottelemaan, mitä minulle tullaan kertomaan leikkauksesta. Selkäydinanestesian jälkeen ei saa nostaa päätä, koska seurauksena voi olla kova päänsärky. Siinä makasin selälläni, tuijotin kattoa. Hoitaja kävi mittaamassa verenpaineen. Eikä hänkään osannut sanoa miksi ihonsiirtoa ei suoritettu. Hoitaja lohdutti minua; että kun lääkäri käy katsomassa niin saan tarkemmat tiedot leikkauksesta. Minut valtasi hirvittävä pelko – avuttomuus – tyhjiys – ajattelin, että melanooma oli jo niin pitkälle levinnyt ettei enää mitään ollut tehtävissä.
[The significance of cancer and personal lifestory]	[9] Mietin elämäni taaksepäin – mitä olen oikeastaan saanut aikaiseksi – mitä vielä olisi ollut tehtävissä – tunsin hirvittävää syyllisyyttä. Ennen kaikkea siitä, mitä virheistä olen tehnyt poikani suhteen ja kuinka hän nyt selviää kun kuolen.
[Being a patient]	[10] Tuli ruoka-aika, osastoapulainen toi ruokatarjottimen pöydälleni ja toivotti hyvää ruokahalua. Siinä minulla oli pohtimista – miten saan syötyä – kun piti olla aivan selällä eikä voinut päätä nostaa. Ajattelin soittaa hoitajaa auttamaan minua, mutta en sitten viitsinyt kun näin että heillä oli muutakin tekemistä. Hamusin ruoka-astian rintani päälle – oli keittoa – onneksi löysin lusikan, muuten syöminen ei olisi onnistunut. Siitä huolimatta osa ruoasta meni kaulalle – eipä minulla ollut edes nälkä. – Kyllä siinä, keitto rinnoilla muuttui täysin elämän arvot. Nyt tajusin – mikä elämässä on tärkeintä – ei se ole raha, ei omaisuus, ei asema yhteiskunnassa – vaan rakkaus ja terveys. [11] Ajattelin potilaan asemaa miten voi nöyräksi itsensä tuntea. Itsetuntoa ei ollut enää lainkaan, olin aivan toisten armoilla. Nöyryyttävää oli virtsata alusastialle, kesti tunti ennen kuin se siihen onnistui. Vaikka

	<p>hoitohenkilökunta oli ystävällistä, niin silti minua vaivasi, kun he puhutellessa käyttivät sanontaa: että kyllähän sinä sen tiedät. He eivät osanneet kuvitella, että olin yhtä avuton ja tietämätön kuin kuka tahansa siinä huoneessa olevista potilaista. Se ei olisi saanut vaikuttaa mitenkään, että olen sairaanhoitaja. Tunsin tarvetta saada lisätietoa, neuvoa, tukea, olisipa joku ottanut edes kädestä kiinni. Minun oletettiin olevan vahva, vaikka tunsin itseni murenevan siihen sairaala vuoteeseen.</p>
[Self-negotiation]	[12] Meni ilta, meni yö, tuli seuraava aamu. Aamun valjetessa oli tehnyt paljon uusia päätöksiä. Mutta miten ehdin ne toteuttamaan, sitä en tiedä.
[Patient-doctor communication]	[13] Tuli lääkärinkierron aika. Osastonlääkäri, osastonhoitaja ja leikkauksen suorittanut lääkäri seisoivat vuoteeni ympärillä, valoisat ilmeet kasvoilla. Kirurgi kertoi leikkauksesta: että melanooma oli pinnalla, eli Clark 1 ettei tarvinnut tehdä kuin lisäeksiisiota ja haava saatiin suoraan suljettua. Kehui vielä minulla olevan tuuria mukana. Mene ja tiedä. Minut kotiutettiin hyväkuntoisena. Ompeleiden poistoon kehoitettiin menemään terveyskeskukseen jollen ota niitä itse pois.
[Post-recovery health condition]	[14] Melanooma kontrollit tapahtuvat myös terveyskeskuksessa, ensin ½ vuoden kuluttua jolloin katsotaan thorax (keuhkokuva) PVK, afos, La. Olen käynyt kontrolleissa kaksi kertaa, mitään uutta ei ole ilmennyt. Tunnen itseni erittäin hyväkuntoiseksi.
[Concerns about her adult son]	[15] Poikani, jonka takia koen valtavaa syyllisyyttä, meni syksyllä 1993 alkoholipsykoosiin, seurauksena oli sairaalahoito. Se oli minulle kauhea paikka. Ajattelin ettei minun melanoomani ole mitään, verrattuna siihen jos mieli järkkäisi. Kävin useita hoitoneuvotteluja. Minulle kerrottiin, että poikani oli ollut kovin huolissaan minusta. Minkä seurauksena hän oli lisännyt alkoholin käyttöä torjuakseen sillä todellisuuden.
[The significance of the help offered by society]	[16] Siinä vaiheessa unohdin täysin itseni. Aloin seuraamaan miten meillä tänä päivänä toteutetaan psykiatrasta hoitotyötä. Näin siinä paljon epäkohtia. Tämän seurauksena, minun oli lähdettävä kehittämään itseäni. Hakeuduin opiskelemaan psykiatrasta hoitotyötä. Nyt parasta aikaa opiskelen. Minulla on paljon tekemistä, niin somaattisella puolella kuin myös psykiatrisella puolella. Poikani on päässyt sairaalasta ja käy jatkohoidoissa mielenterveystoimistossa. Pojalleni rukouksen voimia, että hän selviytyisi elämässä. Oma elämäntilanne on muuten erittäin hyvä.

At the beginning of her story Ruth says that hearing the word melanoma makes her think of a death sentence. She wonders if her existing personal fear towards this illness as a medical student had something to do with her later life [1]. It was the day after the midsummer festivities, Ruth was in love and she felt happy, despite the miscarriage she had experienced recently and her son's problems with alcohol, and then she received a phone call [2]. The phone call came from her physician saying that her birthmark, recently removed, was declared to be malignant. She was thoroughly shocked as she sat on the floor and tried to figure out how to tell the news to other people. In her mind, she goes through the possible reasons for her melanoma: was it the sun, viruses – it had no significance, now she had *it* [3]. She decides to suffer alone, which makes her aggressive and nasty towards others. She hopes that acting like this would mean that no one will miss her when she dies

[4]. A few weeks later she enters hospital. Doctors act helpfully and explain what will happen next [5]. On the evening before surgery she may return home. Then comes the time to tell others the truth. The comforting words make her understand that hidden sorrow may break everything, whereas sharing troubles may help her to find the way out [6]. The next morning she has the surgery [7], which lasts 45 minutes. After that the inner suffering began. She was expecting a skin graft, but no one says anything; why was nothing done? Was the cancer so widespread that there was no longer anything to do? Ruth feels empty and helpless [8]. She begins to analyse her life, what she has done and how. She feels guilty because of her son and would like to fix everything if she had the chance [9]. Being a patient is not easy, for example it is not easy to eat soup laying on your back. Ruth realises that money, fortune or social position are all insignificant compared to love and health [11]. While laying in bed she feels as though she is falling apart, but there is no one to hold her hand or to support her with a kind word. People in the hospital expect her to be strong, as she is a nurse herself, but she is not strong [11]. At night, after the surgery, she makes plans and decisions, although she does not know if she has time to make them come true [12]. In the morning the doctors come and tell her that she has been lucky, as the surgery was successful and the wound was small. Thus, she could remove the stitches herself if she likes [13]. A year after the surgery she feels good [14]. She still suffers because of her son, who became seriously ill because of alcohol abuse. Ruth thinks that her melanoma is nothing compared to disturbance of the mind [15]. She decides to continue with her studies to help people with mental problems. Although she is still worried about her son her life is really good [16].

## **Meaningful 'knots' of time**

For Seth and Hanna, the period before being officially diagnosed with cancer is full of questions about their health. As they were both then in their early thirties, the idea of having cancer or being seriously ill did not occur to them. Their pre-symptomatic health concerns, tiredness, nervousness and lack of concentration, bothered their daily lives and worry them. Hanna actually felt the changes in her body, whereas Seth struggled with his constant stomach problems. They consulted their physicians and at first received incorrect diagnoses and medication. This clearly demonstrates that for physicians too the discovery and diagnosis of cancer is complicated, which makes the situation even more complex.

Ruth, in complete contrast to Seth and Hanna, was not concerned about her health before she received the diagnosis. She lived her daily life being happy, in love and full of energy. Her only concern was her adult son who could not get a grip on his life. Cancer comes to Ruth as a total surprise from nowhere. Only later, when in hospital, did she realise that as a natural redhead, who has adored sunbathing throughout her life, she fits into the typical melanoma schema rather well.

Apparently, the most significant time in the cancer narratives is the moment of diagnosis. This moment polarises human experience, encompassing the period of self-alteration into a cancer patient and the lived events surrounding an individual's cancer experience. When Seth hears his diagnosis he feels relieved because the cause of his six-month suffering has finally been discovered: "I had felt it long enough. Relief, as the troubles with painful haemorrhoids that had lasted months was over. Just haemorrhoids would not influence the whole soul in this way. The confusion of half a year, collapse, the feeling of the world ending, the depression has received a confirmation: Cancer!" [S1] Hanna's first feeling is brief: "Now it is in me." [H4] Ruth, again, writes: "My life was filled with emptiness. I felt like dying immediately, or to be correct, I thought that I could not be dying while I am absolutely healthy, happy and full of life power. I denied it all." [R2]

It is rather common among the cancer narratives that people try to analyse the reasons for their cancer. Accordingly, they observe their lives and physical conditions before cancer was diagnosed. Although most people are aware of rational explanations for falling ill with cancer, the cancer narratives demonstrate that when cancer becomes part of the life-course, people desire an explanation for its occurrence and seek it with reference to their previous lives and daily challenges. Observing and analysing the times before the cancer diagnosis is a predominant and significant act for patients, who recognise the importance of self-help throughout the pathological drama and who become concerned with physical and psychological self-alteration and self-help. Thus, looking for individual explanations for cancer could be seen as an important task that assists coping with the illness, as well as in the search for a way out of the situation.

According to the culturally approved illness course, cancer patients are treated in socially arranged and supported healthcare centres. In reality, both for patients and physicians, the period spent in the healthcare institution is merely outlined by the chirurgic, and other, procedures that removing diseased cells and tissues from the patient's body. Considering the general course of the pathological drama, the events that take place in the

healthcare institutions have particular significance, as during this period people become separated from everyday life and become involuntary members of what could be called the ‘society of sufferers’. According to cancer narratives, being a patient in a healthcare institution means, above all, that people are expected to give up the control over their bodies, even as cancer and its treatments modify it. For many patients, this means that they feel totally lost inside a part of the drama that centres on the physician’s rational approach and medical vocabulary. They feel that their identity becomes loose and that they are not handled as whole beings. The majority of patients find it difficult to acknowledge that only the technical modification of the body can heal cancer. In this sense Seth and Hanna’s stories, particularly, point out that the healing process lasts far longer than the period spent in hospital. Both understand the need for self-help in order to recover, and at the same time they desire spiritual support and advice. Seth decides to eat bran to support his body and thinks about making changes in his life if he survives the summer [S24]. Hanna makes long therapeutic walks and changes her menu while receiving chemotherapy. She argues the need for such self-help as follows [H12]:

Becoming well and taking care of one’s condition, whatever the illness might be, are mostly dependent on one’s will. In my mind I made a clear difference – the doctors take care of their duties and I do mine. For example, if I had not eaten healthily between the treatments, I would have had problems receiving cytostatic treatments because of bad blood counts and the treatments would have been cancelled. Logical, but so hard! Despite this I did not want to become totally helpless, as I saw so many people in much worse conditions and they also managed. Of course I do not believe that I stopped the cancer spreading purely with my will, but certainly I could influence the process of getting better.

Ruth’s story seems, again, different from the others. The surgery is declared successful and she can leave home to continue her life. The general problem with ‘being cured of cancer’ is that this does not really mean the immediate end of the pathological drama. All cancer patients are expected to participate in follow-ups, which bring the fear that cancer has continued to spread without patients noticing it. Ruth, at least according to her cancer narrative, appears to be an ideal patient, who after the surgery is actually well again; the follow-ups, too, show no sign of cancer returning. The cancer experiences described in cancer narratives demonstrate that people may not rely on their bodily awareness. Without modern medical facilities it is almost impossible to discover

cancer early enough and consequently people develop the fear of cancer returning. This also means that for many cancer patients everyday life is, and will be, affected by the fear of dying. Hanna is one of them [H16]:

Until now there has been not a single day (and hardly every will be) without having cancer in my mind. I think it does not affect my daily activities. I am not depressed, I do not have nightmares and I am not afraid of falling ill again. However, I know that I prepare myself for the moment of cancer's return. Thus, I could adapt an old Flora advertisement: What did I think before I fell ill with cancer?

While attempting to regain their place in society, cancer patients are often confronted with sociocultural expectations that stigmatise them. For some people, this means suffering and continuous challenge, whereas others decide to confront societal expectations and continue living, paying more attention to their quality of life as individuals. Seth describes his return to working life as follows [S21]:

Acquaintances and work colleagues were shocked hearing about my case. Certainly they had almost buried me and created a tragic story on top. But I lived, and after sick leave I returned to work and blamed others for the oversights that had taken place while I was away. I think that before I had been too kind, I made promises and I could not say no. As I did so, I did it too harshly. Now I decided that this comes to an end. I did not give a shit. I didn't have much to lose. I had decided to have the next summer to myself, free and in my summer cottage.

According to sociocultural expectation, after the cancer is removed and its spread stopped people get a chance to continue with their daily lives. This period, which in terms of cancer represents the post-recovery period, is represented in cancer narratives as a time that could be called 'afterwards'. During this period, people make attempts to return to their everyday activities. For many cancer patients, this means that they have to accept their changed physical condition. This may be challenging as the surgeries and other cancer treatments are radical and leave their 'footprints' in the body. For Hanna, the biggest problem was that the surgery left her infertile. She is critical of physicians, who did not realise that this might be a great challenge for a woman at the beginning of her thirties. She also expected some advice concerning her sex life after the surgical procedures. As no advice was offered, she had to find the solutions for her situation without professional

support [H14]. The lack of ‘spiritual’ support is a general problem in cancer patients’ writing. This is a phenomenon generally connected with trying to solve personal health problems alone (Seth and Ruth), although this does not exclude the possibility of a real lack of professional support (Hanna). For Hanna and Ruth, their relationships work as powerful wells of spiritual help [H13, R6]. Seth, again, loses his health and with it also his family and previous work colleagues. He decides to find entirely new paths for his life, and according to the final words of his text it seems that he has found happiness and an understanding of life [S25]. According to the cancer narratives, all cancer patients, among them Seth, Ruth and Hanna, have to understand and accept the single truth arising from the process of having cancer – life is a continuous confrontation and response to the fact that we will all die. Accepting this fact is often interpreted in cancer narratives as a valuable lesson about life, in which nothing is self-evident.

One interesting commonplace in Finnish cancer patients’ narratives is the intended use of time expressed in terms of seasonal change (020, 024, 025, 031, 064, 069, 085, 130, 136, 153, etc.). In Seth’s story his argumentation relating to his bodily condition is strongly bound up with the seasons. Accordingly, the spring marks hope for recovery, whereas autumn approaches with lost chances. This kind of polarity in thinking, connected with an individual’s health condition, is an interesting phenomenon. According to the cancer narratives, this kind of reasoning clearly affects people’s decision making as it relates to their health. Being tired and depressed during late autumn and winter seems acceptable for most of the respondents, but when their health does not change for the better during the spring and summer, people decide that there must be something dreadful going on with them.

On a more general level, the significant times in cancer narratives are also connected with festivities and holidays, which have significance in Finnish culture (Virtanen & DuBois 2000, 108–114). In cancer patients’ narratives the period around Christmas, Easter, the 1st of May, Mothers’ Day and the midsummer festivities occur as particularly depressing for cancer patients. They feel confused, when they are expected to be happy and relaxed; the inner confusion or physical suffering denies their expected joy: *Laulut, lahjat, kakkukahvit; miten olisinkaan nauttinut tästä, ellei sydämeni olisi ollut halkemaisillaan.* “Singing, presents, cake and coffee; how I would I have liked to enjoy it, but my heart was about to split” (135). The celebrations important in the family circle, such as birthdays, name days and graduation parties, are also meaningful during the pathological drama, and

thus emerge in the narratives. Ruth feels happy because it is summer (midsummer) and she is enjoying the time of her life. Seth, again, waits to survive the summer after his surgery before making further plans. In a similar manner, many cancer patients connect these culturally significant times with their individual decision making in terms of their illness process.

In the following figure (see Figure 11), I have visualised the evocative times, or temporal ‘knots’, that occur in the context of the cancer experience. These knots may be said to be appropriate when composing a meaningful cancer narrative:

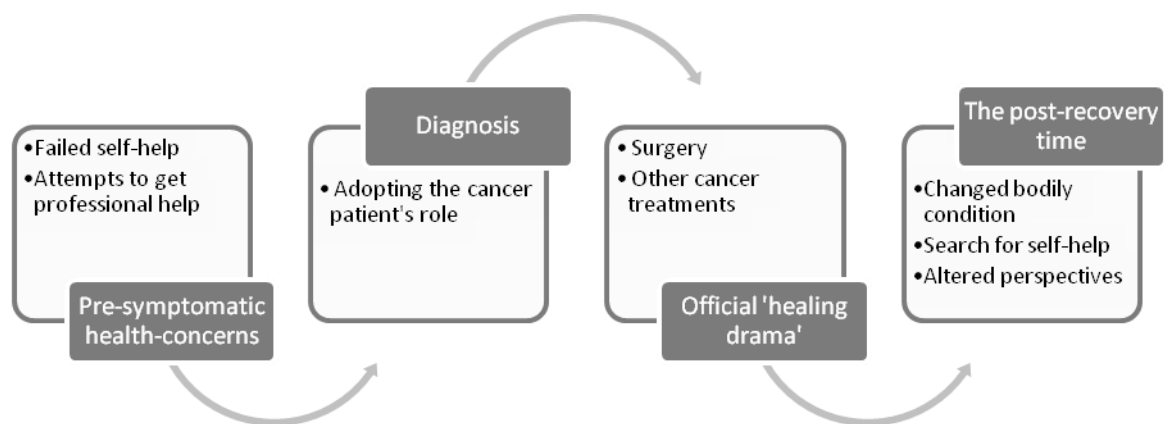


Figure 11. Temporal ‘knots’ in cancer narratives

Consequently, we may connect the four significant time nodes with the structural segments of William Labov’s narrative schema (Labov 1972, 359–370). Having done so, we notice that these evocative temporal segments in written cancer narratives accurately follow the structural principles of narration common to our culture. As a result, the pre-symptomatic health concerns temporal segment creates the necessary setting. The moment of diagnosis functions as complication. The period of the healing drama offers either a positive or negative ‘solution’ to the cancer experience. The period after the cancer experience, or the descriptions of post-recovery time, functions as continuous ‘evaluation’ of the influences of cancer on life. Thus, we may suggest that structural principles relating to the illness process rule authorial speech during the creation of meaningful (auto)pathographies.



## Meaningful ‘knots’ of place

Despite differences in writing style, all the cancer experiences described are temporally bound to the events that occurred during the illness process. At the same time, the intended events and feelings are connected to particular spatial dimensions within the writing, which I shall call evocative milieux. According to the analysed materials, the milieux, or meaningful ‘knots’ of place, most often exploited are the natural environment and everyday settings, as represented by the domestic or work milieu. Typical to the narrating of illness within cancer narratives, the important places are various healthcare institutions, such as healthcare centres and cancer clinics. The analysis of the text corpus also shows that dreams and dream-like visions may be used to mediate some intended meanings in authorial speech. All these spatial dimensions have different meanings within the individual cancer experience. Nature or natural surroundings, for example, are connected with inner feelings and the self-alteration process. The everyday environment reflects the cancer patient’s changed position within the family, at work and within society. For example, when describing his health condition during the pre-symptomatic period, Seth writes [S3]:

Half a year before my diagnosis work-troubles made me nervous; I reacted with my stomach all the time. Every day was for surviving. Work did not make sense anymore. I knew that this had something to do with tiredness and depression, but I was so deeply inside my feelings that the missing reasons, and surviving the tasks, filled up my day.

The hospital milieu is used to evaluate the officially approved healing process, and the dream milieu is used to deal with suppressed thoughts and feelings.

Of these, the most fertile, and at the same time most stable, context for expressing the inner confusion caused by cancer is nature and the natural environment. Because of historical attachments, nature and the countryside are considered traditional environments among Finns (Piela 2006, 277). Nature signifies the continuous lifecycle, which contradicts patients’ ideas about individual life-course. According to popular understanding, falling ill with cancer signifies the end of life. Nature, on the other hand, is experienced as eternal and continuously reborn. The conflict between individual status as cancer patient and natural conditions offers a rich choice for comparisons that communicate significant issues

and situations. For example, Seth used the opposition between individual feelings and the natural environment in the following manner [S2]:

What could have been the reason that life, which despite the years I felt was barely beginning, could stop already? What, yes what? I did not understand.

On the other hand the weather and nature may also be used to support the expression of inner feelings. In Hanna's narrative, the 'grey autumn days' reinforce her thoughts and fears about the possibility of dying. Under such weather conditions, no one seemed to care about her red nose and tears as she endured her dreadful feelings [H11].

The everyday milieu is foremost used to describe the individual challenges of cancer patients at the soci(et)al level. Therefore, a patient's thoughts relating to this include popular expectation, as well as behaviour as it relates to cancer and cancer patients. This leads to the economic and social challenges that effect the status of cancer patients being discussed, along with the course of the pathological drama. Hanna's story shows that money and help from outside have a significant role in survival and recovery [H9]:

I was ill at the time when the state still supported families with kids generously. When I had to go to hospital we always had the same home helper, which helped me a lot. The greatest help for our family was my daughter's godmother, a friend of mine who quit her work in the autumn to take care of me and my child! She lived with us, we took care of domestic work together and I could rest and make walks according to my condition.

Events experienced in the domestic sphere and at work also have an important place in cancer narratives. The respondents are grateful for the support and understanding that comes from family members, close friends and work colleagues, although they find it difficult to talk about their illness and share their sorrows. The respondents expect others to realise the delicacy of the subject, which is connected to the culture-bound image of cancer.

The hospital milieu is suitable for description of the intended aspects of the healing ritual, which, as already mentioned, has an essential meaning for the outcome of the individual cancer experience in the societal dimension. In cancer clinics, a patient's identity becomes loose for several reasons: people lose familiar social settings; they are expected to give up control of their bodily condition; and many patients suffer from both a lack of intimacy and a lack of spiritual support. Although hospitals are meant to offer the

comfort and care required, individuals feel abandoned and vulnerable when placed in such conditions. Accordingly, in their narratives people put forward arguments critical of the patient-doctor relationship and the treatments given in hospital (see Chapter 8; see also Hawkins 1999, 5–7).

We may argue that, if cancer patients feel excluded from daily activities and duties to a certain extent in the everyday environment, then the hospital milieu removes the familiar social context entirely. Although patients are able to observe ‘normal’ life through the hospital window, it appears unrealistic compared to their own situation. Accordingly, writers argue that via spatially bound experience gained in healthcare institutions, people learn to sense nature more powerfully than before, and in this way their everyday lives and personal life stories gain new perspectives (see Chapter 7).

The milieu created by dreams and dream-like images appears noteworthy in cancer patients’ writing. Dreams may be seen as the uniting of events gained in natural, everyday, and hospital milieux. Because of the cultural image of cancer, the illness process causes fear and conflicting feelings in cancer patients and in the people around them. This fear sets limitations on the possibilities of discussing one’s illness and its perspectives with others. Many individual feelings and experiences become suppressed during the pathological drama, although as the suppressed ideas can occur in dreams, people may interpret their dream experiences and everyday lives, and through dreams mediate the thoughts and sorrows that would otherwise remain unspoken. For example, Seth’s dream of being involved in the war leads to the interpretation that he has to do everything he can to help himself out of this critical situation [S11]. In many cancer narratives similar dream experiences seem to frame the whole cancer experience (see Chapter 9).

## **The diversity of voices**

Dell Hymes has suggested that the most fruitful approach to studying texts is what he calls ‘practical structuralism’ or ‘descriptive structuralism’. In his article on Salomon’s myth, Hymes points out that meanings are also conveyed in elements, patterns and relationships, and thus to discover these meanings texts have to be analysed in adequate ways (Hymes 1985, 396). The adequacy of this process is connected to the central idea that the analysed texts have to be observed in their sociocultural and historical contexts. This, above all, means studying the internal and external meanings that authors imply within a thematically united text. In her study on written family narratives, Pauliina Latvala has pointed out that,

in addition to the selected time line, characters who appear in connection with different events, frame the social reality represented in the stories (Latvala 2005, 80). In cancer narratives, the selected milieu may also play a significant part in expressing the author's thoughts and feelings. In this sense, the multi-layered interactive formations, or the 'diversity of voices' that respondents use, is particularly interesting. Most importantly it allows the incoherence characteristic of narratives based on personal experience to be explained. In Bakhtinian terms, the intertextual incoherence may be explained as being due to "dialogized heteroglossia", which he has defined as the authentic environment of an utterance – the environment in which it lives and takes shape. According to Bakhtin, this dialogized heteroglossia is anonymous and social, like language, but simultaneously concrete, filled with specific content and accentuated as an individual utterance (Bakhtin 1981, 272).

Equally significant in this way are the author's intentions when composing the narrative. During the writing process certain tendencies expose the intended goals, such as the influence and meaning of cancer on an individual's life. In terms of understanding authorial intention, the author's evaluation of the whole illness process gains a significant position. Authorial evaluation contains a comparison of periods before and after diagnosis, and also examines inner feelings in different temporally and spatially defined situations. Although this may seem to be an individual negotiation process, it holds a communicative value, which makes the descriptions of individual experiences particularly interesting in an ethnographic sense. This means that the written cancer narratives are, above all, drawn from 'responsive' understanding, showing that "although the orientation is not particularised in an independent act and not compositionally marked" (Bakhtin 1981, 280) it has its goals in terms of reception, which in this case was a writing competition dealing specifically with cancer patients' experiences.

From an ethnographic point of view, the dialogic imagination characteristic to the cancer narratives is particularly significant, as the different authorial intentions convey the individual, sociocultural, and societal expectations of the subject. If we look at the characters who appear in cancer narratives, the dialogic imagination with its intended meanings becomes evident. In Seth's writing, physicians appear in five [1, 12, 18, 19, 24], nurses in one [15], and his wife in three [3, 10, 14] episodes. The other episodes are made meaningful using Seth's own ideas and feelings about the defined milieu. Therefore, considering other materials studied in this work, I emphasise that the most critical inner

feelings are typically drawn out using confrontations between the self and the natural environment [2, 5, 6, 9, 20]. In this sense, the dream milieu also becomes important [11, 16] as it mediates the primary feelings and suppressed thoughts of cancer patients. The everyday environment [3, 5, 7, 8, 21, 22, 23] described in Seth's story is foremost important in the sociocultural sense. This is because during their illness process cancer patients have only a loose connection to the everyday milieu.

Hanna's story, which, when compared to Seth's story appears rather evaluative, contains more active characters. For example, the gynaecologist [2, 3, 5], physician [4, 6, 14, 18], husband [3, 6, 9, 10, 11, 21, 23], daughter [1, 2, 9, 17], sister [3], sister-in-law [8], and daughter's godmother [9]; additionally, in numerous episodes Hanna communicates directly with the organisers of the writing competition [meta-text, 5, 9, 13, 14, 16] in order to answer the questions they posed. In some cases, however, similar episodes may be interpreted as dialogic imagination between Hanna and her individual cancer experience [7, 15, 18].

As in Seth and Hanna's stories, in Ruth's story, characters, family members and hospital personnel are dominant. As Ruth is very much concerned about her son and his life, her son's character appears in several episodes [2, 4, 6, 15, 16]. Ruth's individual concerns also relate to her male friend [2, 4, 6]. Her position as patient becomes evident through oppositions with the physicians [2, 5, 6, 13, 14] and nurses [7, 10, 11] who take care of patients like Ruth.

Consequently, in these narratives the dialogic imagination becomes expressed on three different levels of voicing. Firstly, it is created using characters, such as physicians, nurses, family members or work colleagues, who carry their pre-defined roles into the stories. However, in some episodes, which form the second level of authorial voicing, these characters have only fictive significance, meaning that the author proposes his or her ideas using imagery discussion with the selected personae. Thus, these conversations take place only in inner, or pre-narrative, forms and never in everyday communication. This is also true of discussions on particular milieux, selected to express respondents' inner thoughts and feelings, which form the third level suitable for expressing an author's intentions.

## **‘Voicing’ and the status of the author**

It is interesting that in the narratives analysed, the time spent in hospital gains the central position, although people are convinced that a large part of the healing process is dependent on their own decision making and self-help. The examination of different cancer patients’ narratives points out that hospital events are important because they lead to certain solutions in the cancer battle; however, this is also a period during which issues relating to subject and object become most unclear, both within the narrative action and as they pertain to the author’s status. The main character (protagonist), who in other contexts occurs as an active participant, becomes a passive patient, and thus the protagonist suddenly becomes an object to be treated according to socioculturally accepted norms. Above all, the hospital milieu formalises the patient’s inactive position and therefore has internal and external significance when it comes to attempts to understand written cancer narratives. Particularly when in hospital people find themselves in the undesirable position of being in a situation that is out of their control, a situation out of which, under normal circumstances, they would wish to find a way. In the cancer narratives, the patient’s role is definable as inactive, meaning that the narrative action is in fact targeted towards this person: the action happens *to* him or her.

The author’s status is complicated, as the author has the right to move along and between the chronotopes and intended events within, and outside, the text. The author interprets the lived events and composes the story following his or her own intentions and narrative goals. This is a significant part of verbalisation and interpretation process, which participants are well aware of:

*Yleisesti puhutaan, että muistelemisessa ei tuoda esille omia heikkouksia. Asiat esitetaan sellaisina miten ne halutaan muistaa. Kertomukseni on jonkinlainen muistelman sekin, joten siinä esitettyjä asioita on aika myös varmasti siloitellut, kaunistellutkin. Olen joka tapauksessa yrittänyt olla rehellinen kertoessani syövästäni sekä lyhyesti ennen ja jälkeen tämän kaikkien pelkämään sairauden.*

They say that generally, when recalling memories, a person does not bring up his or her own weaknesses. Things are put forward as people want to remember them. My story is a sort of reminiscence as well, so the things given here have certainly been smoothened and even highlighted by time. However, I have tried to be honest, telling briefly about my life before and after this illness that is feared by everybody. (650)

Accordingly, the author employs voicing to expose his or her ideas and make them understandable. The main problem here is that the author's personal voice is controlled by culture-bound expectations, which in this case refers to the cancer patient's stigmatised role in everyday life. Therefore, when talking about cancer narratives, it is difficult to decide which kind of author voicing belongs to the external, such as culture- and language-bound ideologies, and which to the internal or personal set of cancer-related ideas.

The voice of the respondent in the written cancer narratives is constantly evident, which is characteristic of ethnographic description of lived experience. The authorial voice may appear and disappear as the author finds it useful. Considering the context of the writing competition, the respondents' voices may be interpreted as ethnographic, and thus objective. This also means that the author's status is fixed, for instance by the personal data added to the writing. In the sense that this author's status appears as stable, at least so far, we do not gain any additional information about this person. However, as with Hanna and Ruth's stories, and in the final episode of Seth's story, the respondents continuously comment on, and evaluate, the information they have given, and here we can no longer be certain that these are evaluations in an ethnographic sense (objective) or if these ideas follow the author's arguments regarding his or her position as a cancer patient (subjective).

The 'responsive' orientation of self-expression makes it particularly debatable whether the writing sent to the archive contain merely subjective values, or whether they represent objectivity. It is impossible to claim that the author's identity could be approached as a stable element. This becomes evident within the narratives, where the author's status in the socioculturally defined role of cancer patient is approached as being in constant flux. Thus, I emphasise that the identity alteration that appears typical in cancer narratives is to some extent caused by the conflict between the individual's experience and culturally agreed ideas about cancer. Although the author as the main protagonist is an active role in all situations, the patient's role is interpreted as entirely inactive within the sociocultural setting. This means that to create a culturally acceptable story about an individual's cancer experience, the author must agree to accept the cancer patient's role, which apparently culminates in the hospital milieu. However, as the individual experience is in many ways different from cultural expectation, the author also attempts to deny this pre-set passive role. Consequently, we have to see authorial speech in cancer narratives as a continuous

negotiation between the personal voice and a culture-bound role. This negotiation also affects the author's status, both inside and outside the narrative events.

## Conclusions

Despite the fictiveness characteristic to narrative representations, evocative 'knots' of time and place must be approached as valuable in the study and comprehension of the cancer experience from multiple perspectives. Here I emphasise that the great part of understanding cancer patients' writing, and the respondents' intended ideas, relies on our socioculturally bound understanding of processes that concern this particular illness. The schematic structure of cancer-related events has a particular function in bringing together the respondents and their audience. Evocative times relating to certain milieux may be interpreted as a author's attempt to mediate the opinions, ideas and feelings that cancer patients experience at various communicative levels. Furthermore, the 'dialogic imagination' characteristic to cancer patients' writing allows expression of the author's experiences and ideas, not only at a communicative level, but also – by conveying thoughts that have never been externalised before – at the level of thoughts and feelings.

Naturally, cancer narratives, like any set of self-expressive texts based on personal experience and cognition, are multi-layered. The most significant differences here derive from the individual illness course underlined by the unique nature of cancer. The symptoms of cancer may be vague and even nonexistent. Despite this, the period before the diagnosis has an important place in cancer narratives. This may be understood as the writer's intention to analyse and suggest possible causes for the disease. On the other hand, as with Ruth's story, it can be a way to show how the cancer diagnosis changes a life in seconds. The moment of diagnosis is described carefully, which indicates its significance within the narrative. After the diagnosis is given, the official healing drama begins. The time spent in hospital is crucial, because according to sociocultural understanding it is the only way to stop cancer. People realise quite quickly that help from doctors is not enough to become well again, and they attempt to regain control over their body and life via important decisions about various self-help techniques. The period that I have defined here as 'afterwards' is equally significant. It allows description of the changed life situation and the patient's attempts to participate in everyday life as he or she had before. Some patients



are more successful than others in this, although all learn lessons that leave imprints on their lives. In contrast to survivors, for respondents without hope of recovery, 'afterwards' signifies the relief that comes when they pass away.

Close examination of Ruth, Hanna and Seth's cancer narratives allows the suggestion that the intended meanings, and the diversity of voices in the written texts, predominantly aim to fulfil certain extratextual expectations connected to a potential audience. Accordingly, the meeting points of time and place in cancer narratives are used to describe changes in the status for respondents when they have cancer. In this sense, the narrative structure characteristic to cancer narratives is affected by the culturally accepted idea that a person's status before falling ill becomes somewhat looser after the cancer diagnosis. As a result, in their writing the respondents are concerned about lost self during the pathological drama. The 'dialogic imagination' is used to express the self-negotiation processes as it relates to particular milieux and characters.

Above all, our attempts to understand the intended internal and external factors in cancer patients' writing is dependent on our willingness to comprehend. The texts in which respondents claim that there was no alteration at all are rare among the studied materials. Because of sociocultural expectations relating to the image of cancer as a lethal disease, it is difficult, foremost, to accept these texts as 'truthful' in an ethnographic sense, and furthermore without the individual alteration process, these stories would also be insignificant as personal experience narratives. Because of socio-historical context and the popular image of cancer as secretive and lethal disease, which I discuss in subsequent chapters, our understanding of that illness is restricted. However, where we approach cancer narratives as 'wholes', paying attention to the intertextual and extratextual aspects that 'centre' these texts in the current interpretative matrix, we may discover that written cancer narratives express far more than simply what is expressed in the described events.

## **5 Popular Images of Cancer in Modern Discourse**

The culturally defined meaning of cancer, that of a serious illness, the expectations of patient illness behaviour and their processes of adopting the role of patient are central themes in the cancer patients' narratives analysed in this work. The heterogenic nature of cancer narratives makes it possible to understand why there is a great difference in individuals' interpretations concerning the various culturally accepted expectations connected with cancer. The differences are understandable because of the variations in personal cancer experience and the individual's life in general. Despite these differences, the available interpretations often tackle similar themes and topics to those that appear as characteristic to the culturally framed discourse on cancer.

In this chapter I shall discuss how cancer is patterned and interpreted within wider society, as illustrated by the cancer narratives. To understand the meaning of cancer in popular discourse I use the concept of explanatory models, suggested by Arthur Kleinman in his study on patients and healers within the context of culture (1980). In his work, Kleinman deals with illness narratives from different cultures and says that explanatory models are responses to particular situations and are therefore idiosyncratic, changeable and heavily influenced by both personality and cultural factors (Kleinman 1980, 104–118). As a result, explanatory models, when applied to illness, consist of notions about an episode of illness and its treatment as employed by all those engaged in the illness process. According to Kleinman, explanatory models are partly conscious and partly subconscious, and are characterised by vagueness, a multiplicity of meanings, frequent changes and the lack of sharp boundaries between ideas and experience. The basic idea of explanatory models in healthcare is to guide a person through a particular illness process or pathological drama by finding the correct cause of the condition and negotiating the appropriate treatments.

In this thesis I am interested in how people explain cancer as a culturally meaningful illnesses from a personal point of view. Here again, I wish to reiterate that popular reasoning is framed by the linguistic ideologies that mediate culture-bound ideas. Thus, the construction of a particular discourse is based on individual, and also cultural, factors. This means that when people are diagnosed with cancer, an internal dialogue occurs between their culturally agreed understanding of cancer, and its meaning to that person. Such reasoning is constantly modified, being specified and re-interpreted based on individual

experience. In this way people create their personal explanatory models, which, although unique, provide five main aspects to illness (Helman 1981, 549):

- The aetiology or cause of the condition (Why has it happened? Why has it happened to me?)
- The timing and mode of the onset of symptoms (Why now?)
- The pathophysiological process involved (What has happened?)
- The natural history and severity of the illness (What would happen to me if nothing were done about it? What are its likely effects on other people?)
- The appropriate treatments for the conditions. (What should I do about it?)

Despite the vagueness and different interpretations occurring in the materials under the study, I argue that the explanatory models relating to cancer form a set of tradition-based beliefs comparable to the ethnomedical records explored in the previous chapter. Like any other set of popular beliefs, respondents' ideas on cancer are heterogeneous and contradictory. Guided by language, people perceive these culture-bound ideas during the socialisation process and thus a particular cultural context takes on its characteristic features. Features that are then compared with individual experiences. As human understanding is open to continuous interpretation, individual interpretations are likely to correct themselves through contact with surrounding culture and in this way a certain stability is maintained. In this manner certain discourses and their characteristic features are defined.

Within the literary sub-group that is pathographies, this culture-bound inner negotiation becomes fixed on paper. Firstly, people reconstruct their illness experience: they point out their individual coping methods, describe the illness process and relate their private attempts to understand the significance of cancer in their lives. Thus, secondly, the result is that tradition-based folk beliefs become contextualised, and are therefore more open to interpretation than the ethnomedical records examined in the previous chapter. Thirdly, when analysing these beliefs or explanatory models, it is important to remember that these discussions, fixed in writing, represent at the same time the writer's inner reasoning and culture-bound ideas, as well as being their response to a questionnaire destined for the

archives. These three aspects form the basis for the ‘dialogic imagination’ characteristic to ethnographic writing.

## The problematic concept of cancer

Today the concept of cancer often causes people some controversial feelings. Many writers admit they despise the sound of the word. Therefore, when participants write about the process of their illness, they avoid the use of the word cancer. Doing so may be interpreted in this context as an ideology reflecting culturally developed ideas relating to cancer. This ideology restricts word use and sets boundaries on individual self-expression. It is very common for the term ‘cancer’ to appear in cancer patients’ narratives deictically. Which is to say that instead of using the noun ‘cancer’, people refer to their illness using the pronoun *se* (it) or *tämä* (that). Respondents use various euphemisms, which, in their minds, describe the aggressive nature of cancer: “*Vielä tänäkin päivänä yritän kaiken mahdollisin keinoin välttää joutumasta käyttää sanaa ‘syöpä’. Siihen liittyy niin paljon kipeitä tunteita. Sen sijaan yritän löytää aina jonkun lieventavan ilmaisan, kuten ‘sairaus’.*” “Until today I try avoiding the word ‘cancer’. It has such a strong connotation with feelings that hurt badly. Instead I try to find some more appropriate word, like ‘illness’.” (418). In the cancer narratives, cancer is called a *piru* (devil) (144), *spitaali* (leprosy) (414, 646), *paha* (evil) (070), *rutto*, *ruttotauti* (plague disease) (033, 136), *käärme* (snake) (095), *susi* (wolf) (383), *vieras* (stranger) (126), and *kuolema* (death) (012, 025, 058, 223, 560, 566, etc.). In order to avoid naming cancer, people write about their body having lumps and bumps (*nystyrä*, *rupi*, *mökky*, *pahkura*, *mätäpaise*). Some of these names will already be familiar from the ethnomedical data described in the previous chapter. Calling illnesses by ethnonyms like devil, evil, wolf or snake was equally common in Finnish folklore.

Several metaphoric expressions are also used to mediate the malevolent nature of cancer. People imagine cancer as something that *syö* (eats), *nakertaa* (bites), or *mädättää* (rots) the body: “It eats me, bites, and rots me” (627). It “enters”, or “conquers”, the human body without the owner’s permission and rapidly changes their life. One participant wrote:

*Sana syöpä on niin ikävä, että itse haluan käyttää sanaa pahanlaatuinen kasvain. Syöpä on kuin “syöpäläinen” rotta, jyrsijä, jotakin kauheaa mikä jyrssii ihmisen loppuun ilman toivoa. Sana pitäisi muuttaa pehmeämmäksi. Itse sairaudesta on tarpeeksi.*

The word cancer is so awful that I prefer the words bad-natured growth. Cancer is like a ‘parasite’ rat, gnawer, something awful that gnaws the person entirely without any hope. They should change the word to be milder. The illness is [hard] enough. (612)

*Mikä on syöpä? Syökö se jotenkin ihmistä ja kuinka? Onko se jonkinlainen mato, joka nakertaa pala palalta? Rakas mummu, se mato syö mummun. Rankaiseeko jumala minua, kun olen ollut tottelematon ja laiskakin, haaveillut kaikenlaista ja ajatellut vain itseäni.*

What is cancer? Does it eat people, and how? Is it some kind of worm that eats piece after piece? Dear granny, this worm eats my granny. Does God punish me because I have been naughty and lazy, dreaming about everything and thinking only about myself? (434)

*Sana syöpä on kauhea asia kun se kerrotaan. Kaikki eletty elämä tulee kuin yhdessä hetkessä silmien eteen. Siinä miettii, miksi on elänyt, miksi on tehnyt niin kovasti työtä, kun pitää näin kärsiä.*

The word cancer is such an awful thing as it is told. All lived life comes like in one moment in front of your eyes. There you think, why have you lived, why have you worked so hard if you have to suffer so much. (163)

Images of illness as some sort of malicious outsider are considered typical to primitive cultures. Cancer narratives composed by Finns in 1994 allow the suggestion that people continue thinking in such a manner today. First and foremost it indicates that people respect the power of words, and that they subconsciously sense that by naming the illness it might gain power over them. In the context of cancer narratives, avoiding the word cancer may be interpreted as an ideology reflecting the culturally developed ideas relating to cancer. This ideology restricts the word’s use and sets boundaries on individual self-expression in modern cancer discourse. However, as is typical to folk belief, this idea also works the other way around: by giving illness a name and shape we gain control over it.

In cancer patients’ minds the concept of cancer lacks certain qualities required for it to be explained rationally. One leukaemia patient even demanded: “*Sairaudella täytyy olla nimi, muttā myös olemus tai muoto*”, “an Illness needs to have a name, but also a shape or form” (506). Thus, we may suggest that without giving illness a proper name and shape it is difficult to unite the illness with personal explanatory models. Personification, or at least naming an illness, makes it acceptable for patients and helps the coping process to continue. This kind of reasoning is independent of scientific cancer discourse.

The scientific explanations relating to cancer also demonstrate that, from the biological point of view, carcinomas are particularly challenging to define. The British evolutionist Mel Greaves has pointed out a significant aspect of cancer, namely that, “the illness we call cancer has extraordinarily diverse features including its causation, underlying pathology, clinical symptoms, therapeutic response, and outcome or chance of cure. In a sense, every patient’s cancer is unique, which is part of the difficulty” (Greaves 2001, 3). This means that cancer represents a collection of numerous disorders of cell and tissue function and that the only special biological property in common is the territorial expansion of a mutant clone. For medical doctors, this means that they are able to make various suggestions regarding the possible illness origin, but these suggestions according to the current state of cancer studies have something like 80% certainty. It also means that because of cancer’s unique nature, every time it occurs, it is challenging to recognise the symptoms, suggest appropriate prevention methods or decide on suitable treatments, or to make a prognosis regarding the outcome. As I shall demonstrate below, for cancer patients this means that their primary question: *why me and why now?* is often left without an answer, and it also means that in reality people cannot compare their individual illness process with other seemingly similar cancer cases. As doctors are unable to give rewarding answers, either because of the lack of biological evidence or adequate communicative (read: healing) skills, patients negotiate their lives and living conditions and come up with popular explanatory models, including their own interpretations of cancer’s name and shape, and also its origin and possible cures. As the cancer narratives indicate, such interpretations are typically based on personal life and lived experience.

Before moving further, I wish to emphasise that because of this ongoing unawareness of cancer, the concept of cancer has gained two meanings in everyday communication: rational and irrational. Rational meaning relates to the numerous cell and tissue dysfunctions that take place in the human body, and in this context the human body is interpreted as a dysfunctional physical object that must be mended. This approach is common among medical professionals and scientists, although from the cultural point of view other people also share this reaction. For patients, cancer’s rational meaning is mainly connected with bodily experience, such as tests during follow-ups, surgery, chemical treatments, and the period of recovery. On the other hand, among ordinary people cancer also has an irrational meaning connected on an emotional level to human suffering, pain, and death. It may be described as a ‘sense experience’ deriving from socio-historical

context. Approaching cancer as a sense experience allows an explanation of why, in popular discourse, cancer is often recognised as an ‘evil being’ with supernatural qualities.

When analysing popular discourse it is not possible to make a clear distinction between the rational and irrational meanings of cancer because during the communication process people employ both meanings at the same time (Quine 2008, 64–65). This indicates that the rational and irrational meanings have to be interpreted as incoherent and overlapping concepts; and where differentiation is required, the speech situation proposes which meaning is to be used.

## Common problems associated with recognising cancer

The previous diachronic insight into Finnish folk medicine revealed that compared to other illnesses, cancer had a secondary relevance in the past (see Chapter 3). The rapid growth of cancer occurrences among the Finnish population has changed the position of cancer among other illness, so that during the second half of the 20<sup>th</sup> century it became one of the most significant illnesses. This increase in instances of cancer (Koskenvuo 1994, 43) has also affected people’s attitudes towards the illness. In contrast to previous times, cancer is no longer considered an illness that only affects old people:

*Lapsuudessani pelkäsin, kuten sen ajan lapset yleisesti, pimeään ja kummitusten ohella tulirokkoa ja lapsihalvausta, isona poikana jo keuhkotautiakin ja kovasti. Pakollisia tuhka- ja vesirokkoja ei pelätty. Kurkkumätä ei myöskään kuulunut tavanomaisten pelkojen joukkoon ja kun vain vanhoilla ihmisillä saattoi olla kasvi, sitä ei ollut syytä pelätä. [---] Sodan jälkeen ei keuhkotauti enää ollut kovin yleinen. En pelännyt sitä ja olin varma, etten sairastu siihen. Sydänvika oli myös unohtunut. Mutta oli tullut uusia tauteja, kuten syöpä. Syövästä alettiin puhua yleisesti. Entisestä vanhojen ihmisten taudista, kasvista, oli tullut syöpä, syöpäkasvain.*

In my childhood, as was common to children of that time, I was afraid of darkness and ghosts, but also scarlet fever and polio, and as I grew older I was also very afraid of tuberculosis. Measles and chicken pox were seen as compulsory, but they were not something to be afraid of. Diphtheria did not belong among the usual fears and as only old people had growths there was no need to be afraid of this. [---] After the war tuberculosis was not so common. I was not afraid of it and I was sure I would not get it. I also forgot about heart failure. But new illnesses had appeared, like cancer. People began

to talk about it. The old people's disease, 'growth', had become cancer, carcinogenic growth. (650)

In her book *Laientheorien zum Krankheitsbild "Krebs"* (Lay Theories about the Image of Cancer, 1989) German folklorist Gudrun Schwibbe points out several interesting problems that people face when they deal with cancer. Schwibbe's study demonstrates that although the popular beliefs concerning the illness origin, symptoms, prevention, treatments and prognosis are close to scientific statements about cancer, people are in many ways confused by these explanations and have a constant need for more accurate information (Schwibbe 1989, 161–162). For example, the most common symptoms of the early phases of cancer are tiredness, loss of appetite and weight, paleness, and in some cases also continuous fever or pain. The main problem is that many of these symptoms can also be psychosomatic, and if these symptoms appear at times of external tension, such as work pressures or partnership problems, people hesitate for a long time before they seek medical advice, which then reduces the chances of recovery.

The fact that the cause(s) of cancer is/are still not entirely clear raises aspects for discussion. According to the cancer narratives, people have problems connecting pain with cancer. This is illustrated in, for example, official descriptions of breast cancer symptoms, which state that pain in the breast should, at least typically, not be considered a sign of cancer (*Rintasyöpä*). Individual experience (and belief), however, is the opposite:

*Kun nyt kelaan tapaukseni kulkua mielessäni, muistan kun eilistä päivää kesää 1976, jolloin rupesin tuntemaan outoa kipua vasemman rinnan kohdalla. Syöpä ei edes käynyt ajatuksissani, koska se vähä, minkä rintasyövästä tiesin oli, että se ei ainakaan anna kipuoireita. Näin ollen oletin syyksi jotain muuta, esim. ylirasitus puutarhatöissä tms.*

As I now rewind the events in my mind, I remember the summer of 1976 as it were yesterday; then, I first began to feel pain in my left breast. The possibility of having cancer never entered my mind as the few facts that I knew about cancer said that cancer never caused a feeling of pain. So I considered other reasons, for example doing too much in the garden or something like that. (147)

On the other hand, the valuable information that cancer organisations share has makes people aware that lumps or bumps suddenly appearing in the body could possibly have carcinogenic origins. For the same reason, blood or other suspicious liquids in excrement



or urine, and also connected with breasts or birth marks, are also taken very seriously and interpreted as *pahan merkki*, or the “sign of evil” (070).

According to the cancer narratives, trained doctors also have problems recognising cancer. As a matter of fact, in numerous narratives people describe their efforts to be taken seriously by professionals working in the healthcare system. As they point out, some doctors also make their primary decisions based on popular beliefs:

*Ensimmäiset lääkärin sanat olivat: “Ette ole ollenkaan sellainen ihminen, joka voisi sairastua syöpään”. Olinko minä jokin erikoistapaus? Minulla oli silloin korkea kolesteroliarvo, peräti 17. Oliko se syy? Silloin lääkärit olivat vielä yli-ihmisiä, enkä minä uskaltanut avata suutani kysyäkseni mitä lääkäri tarkoitti.*

The first words that doctor told me were: “You are not at all this kind of person who could fall ill with cancer.” Was I some kind of special case? At that time my cholesterol level was 17. Was that the reason? At that time doctors were superhuman and I was afraid to open my mouth to ask what he meant. (030)

*Tilaan lääkärin ja lääkärissä olen jo tammikuussa. Lääkäri vähättelee asiaa ja sanoo, että syöpä on kovin harvinainen rinnassa näin nuorella. Odotellaan, kyllä se siitä häipyy. Mutta eipä tämä kaveri häivy. Itsepintaisesti se vaan siinä jököttää. Helmikuussa olen lääkärissä jälleen, mutta lääkäri ei anna lähetettä vielääkään jatkotutkimuksiin. Rauhoittelee vain.*

I make an appointment and visited the doctor in January. The doctor underestimates my concerns and says that breast cancer is very uncommon among such young people. Let us wait and it will disappear. But this fellow does not disappear anywhere. It stays there persistently. In February I make another appointment, but the doctor still does not give a recommendation for further investigation. Calms me only. (048)

*Kesällä tuli iso 7-8 cm kyhmy vasempaan rintaan. Kaksi eri lääkäriä sanoi vieläkin, ettei syöpä voi olla noin suuri ja kipeä.*

In summer came a big 7-8 cm bump into my left breast. Two different doctors still said that cancer cannot be so big and painful. (271)

*Gynekologi tutki rintani ja totesi, ettei siinä ole mitään vakavaa. Hyvästellessämme hän sanoi: “Muistakaa rouvva, syöpä ei koskaan arista!”*

The gynaecologist examined my breast and as I left she told me: “And remember madam cancer never hurts.” (044)

The criticism towards doctors' perceived incompetence is somewhat characteristic to cancer narratives. It appears that people are only given limited opportunity to discuss their health condition and treatments and to give feedback during the pathological drama. Of course there are numerous reasons why people do not share their suspicions directly with people, doctors included, who possibly underestimate their reasoning ability or act in other ways disrespectfully. However, it is understandable that people who are concerned about their health, also feel miserable and are afraid - or do not have the energy - to be assertive or criticise. Therefore, the writing competition was an excellent possibility to share these ideas about doctors' behaviour and decision making during the illness process (see also Chapter 7). The critical descriptions available in cancer narratives indicate that sometimes patients must be highly motivated and stubborn when demanding further procedures:

*Terveyskeskuksessa jouduin nuoren, penseän lääkärin puhutteluun. Vahingossa, ehkä pelkkää väsymystäni tulin maininneeksi hänelle syöpäepäilyistäni. Hän suorastaan kimmastui:*

*“Jaha, diagnoosikin on valmis, kannattikos tänne enää tullakaan?” Selitin varsin rauhallisesti, että tarvitsen lähetteen N:lle.*

*Hän keskeytti ja tokaisi: “Meiltä menee gynekologiset potilaat K:lle, edellyttäen, että aihetta on. Mutta en minä usko, että teillä mitään syöpää on. Johan sitä tuossa iässä sienimetsässä voi vuotoa tulla ilman syöpäkin.” Ääni ja eleet olivat uskomattoman ylimieliset.*

*Koetin rauhallisesti selittää koko sairaushistoriikin jo alkukesästä alkaneesta vuodosta. En ollut käynyt lähelläkään metsää silloin.*

*“Onko se vuoto kovempaa kuin teidän normaalit kuukausivuotonne, vai vähäisempää?”*

*“Kuukautisvuoto: Hyvänen aika olen melkein seitsemänkymmenen. Missä tuo miekkonen oikein elelee, kun luulee minulla vielä olevan kuukautiset. Olihan heti alkuun kertonut saavani vain estrogeenia, eikä se ylläpidä jatkuvia kuukautisia.”*

*“Ai eikös teillä olekaan kuukautisia? Minkä takia?”*

In the healthcare centre I met a reluctant young doctor. By accident, perhaps because of my tiredness, I mentioned my doubts about having cancer. He almost lost his temper:

“Oh, you have already diagnosed yourself, any reason of coming here at all?” I explained quite patiently that I needed a recommendation to N. hospital.

He interrupted me and said: “Our gynaecological patients all go to S. hospital, in case there is a need for that. But I do not believe that you have cancer. At your age one may have bleeding while picking mushrooms in the forest just like that without any cancer.” His voice and gestures were totally arrogant.

I patiently explained my illness course and about the bleeding that started early in the summer. I had not been anywhere near the forest at that time.

“Is this bleeding harder than your normal menstrual-bleeding, or less hard?”

“Menstrual bleeding: for God’s sake I am almost seventy. Where is this guy living that he thinks that I still have menstruation. I had said in the beginning that I take estrogens and it does not keep the menstruation ongoing forever.

“Oh, you do not have menstruation? How come?” (024)

I have selected this example as one of the most striking among the analysed materials describing patient-doctor negotiation about the possibility of having cancer. If it did not represent the daily struggle of cancer patients, the story, in which an almost 70-years-old woman is rebuked and then misunderstood for not having a regular menstrual flow, might even be interpreted as amusing, in a disastrous way.

People have problems recognising and accepting cancer because of its vague or sometimes almost nonexistent symptoms and physical consequences. This also means that if cancer is diagnosed during the officially supported follow-ups, and removed during surgery without further complications, it is difficult for patients to admit to being ill and then being well again:

*Se onkin tällaisessa sairaudessa vaikeaa, kun todetaan sairaaksi, eikä kuitenkaan tunne itse eikä näy ulkopuolelle, jotta on sairas, sekä hoitojen jälkeen sanotaan, jotta nyt olet terve. Miten voi muuttua sen mukaan sairaasta terveeksi, kun ei ole tuntenut itseään fyysisesti sairaaksi kuin leikkausten jälkeen. Sama asia on vaikea myös perheelle, kun on sairaslomalla ja kuitenkin voi suorittaa kaikki kotityöt. Sääli on kuitenkin pahinta, silloin tuntee sairastavansa sairautta johon liittyy paljon mystiikkaa, kuin olisi leimattu.*

The worst thing about this illness is that they tell you that you are ill, although you do not feel ill and it is not visible from outside, and then after treatments they say you are well now. How can you change accordingly, from ill to healthy, if the only time when you have felt ill was after the surgery? It is difficult for the family as well – you have illness leave, but you can't do the housework. The worst things about it is the pity, then you get the feeling that you have an illness that holds within lots of mystery and you feel labelled. (130)

This example represents the change in 'typical' illness course characteristic to cancer, which is foremost caused by medical developments. Because of increased cancer awareness, state supported follow-ups, and highly sensitive diagnostic techniques, carcinogenic illnesses are discovered before people themselves even notice that they are ill. In cases where treatments are successful, it may happen that the process of acceptance or denial of the culturally set stigma, usually described as the feeling of 'being labelled', is more important than the bodily experience and physical suffering connected with cancer. Feeling labelled by cancer is a dominant sensation among cancer patients and therefore I shall return to this question in the final part of this chapter. Before that, however, I would

like to introduce modern cancer aetiology among Finnish cancer patients in comparison to folk medical materials.

## Popular cancer aetiology

In a similar way to the ethnomedical records, the cancer narratives analysed in this work contain various theories about the reasons for falling ill with cancer. The studied materials indicate that as long as cancer concerns ‘other people’, and not ‘us’ or ‘me’, the rational explanation is fine, but when cancer becomes an individual problem it immediately becomes interpreted as a particular illness with a particular significance in the person’s life. Cancer patients’ narratives indicate that this meaningful illness needs an explanation that encompasses the person and his or her personal history, as well as the external and internal factors responsible for cancer. Although today people have lost their contact with the mythological worldview, the underlying idea about illness as some kind of independent being, approaching people from outside, is captured in language and in basic models of thinking. Accordingly, cancer is imagined entering the human body in order to destroy it, whereas the human task would be to understand its origin in order to implement a cure:

*Minulle tuli vieras. Se ei ilmoittanut etukäteen tulostaan. Kun se tuli, se asettui hiljalleen taloksi, valitsemaansa paikkaan. Se ei häirinnyt olemassaolollaan pitkään aikaan, vasta myöhemmin sen läsnäolon vaistosi. Silloin se alkoi tarvita minun apuani ja energiaani varmistaakseen olotilansa ja siitä seuranneen kasvamisensa. Tajusin, ettei tämä vieras ollut minulle tarpeellinen, eikä sen olemassaololla ollut hyvä tarkoitus. Siksi sen paikka ei olisi luonani, emme siis koskaan voisi asua yhdessä. En ollut kutsunut sitä vieraakseni, joten minulla oli valtuudet järjestää se pois luotani....*

I received a guest. It did not let me know about its coming beforehand. When it came, it settled quietly to stay forever. It did not bother me, until later I sensed its existence. It needed my help and energy to be safe and continue growing. I understood that this guest was not welcome and it had no good plans for me. Therefore, its place would not be by me and we could never live together. I had not invited it, so I had the right to get rid of it. (126)

This example describes, in a figurative manner, the nature of cancer as a secretive illness that enters the human body without asking permission or giving any signs of its existence. At some point, however, something internal or external connected with the individual's life *laukaisevat*, 'triggers', the illness and cancer gains control, not only over the body but also over life itself. According to popular thinking, in order to free oneself from this intruder it is necessary to find the primary reason for falling ill. This may be done only by observing the self, with its inner qualities and individual action, in everyday life. Because of culturally shared knowledge, people have various reasons in mind for what might have 'set off' their illness. Here again it is not possible to give any accurate classification of the popular explanations, as individual attitudes towards these explanations are extremely controversial. Some respondents disagree with the generally accepted aetiologies and thus their narratives may be seen as attempts to prove that the usual explanations are untrue, at least in their own case. Others again adopt existent aetiologies, even if these seem totally irrelevant.

To characterise the popular thinking about cancer aetiology expressed in the analysed cancer narratives, I have adopted the categories suggested in Gudrun Schwibbe's work based on German cancer patients' health beliefs. In her study, Schwibbe divided popular explanations for the origin of cancer into six categories (Schwibbe 1989, 51–52), as follows:

- (1) *unclear*,
- (2) *natural/external*,
- (3) *natural/internal*,
- (4) *psychological/external*,
- (5) *psychological/internal*,
- (6) *behaviouristic*.

Applying Schwibbe's categorisation is problematic because any classification is based on a researcher's subjective expertise. Therefore I shall explain briefly how I have differentiated the materials into the given categories. Firstly, the difference between the external and internal natural reasons is made based on the possibility of individual decision making. For example, people cannot protect themselves from pollution, legally used chemicals, catastrophes or genetic predisposition, although they are able to make decisions on food intake, smoking or using particular drugs. Secondly, the categories describing psychological impact are divided based on similar reasoning; the external aspects are based on social tensions while the internal aspects derive from inner problems. The final category contains reasons that are dependent on individual behaviour and action. Here, the external

reasons contain ideas of illness as punishment for individual behaviour, or connect cancer more generally with modern life and lifestyle. The internal reasons, on the other hand, represent certain inner qualities, which, according to popular reasoning, represent a particularly good trigger for cancer.

In the following table (Figure 12) popular explanations, including those with which cancer patients do not agree, are expressed in terms of reasons found in the cancer narratives analysed in this thesis. This table does not contain any quantitative accuracy, because my main intention is to demonstrate the main ideas characteristic to popular cancer aetiology in modern Finland.

	<b>External</b>	<b>Internal</b>
<b>Natural</b>	cigarette smoke, accidents (mechanical injuries), agricultural chemicals used in the 1950s, sun, solarium, contagious diseases, genetics, the Novaja Zemlja nuclear detonation (1961), asbestos, underground water streams, tight clothes/underwear, cosmetics, the Chernobyl catastrophe (1986), polluted rain, poisoned urban air, X-rays, pollution, viruses, electricity	giving birth, losing weight, smoking, hormone treatment, being overweight, food intake, drinking habits, being underweight, lack of vitamins and minerals, getting cold, drinking coffee, one night stands, no children
<b>Psychological</b>	work pressure, marriage crisis, old maid status, loss of a close relative, financial problems, single motherhood	negative thoughts, fear of cancer, sadness, feeling insecure, stress/depression, sorrow, pessimism, inner pressures, hate gathered inside, anger
<b>Behaviouristic</b>	punishment, bad karma, balance for a good life, difficult childhood, war, lifestyle, illness	cancer type, bad nature, personality, self-destructive behaviour, wrong thinking, being too nice, weak nature

Figure 12. Popular cancer aetiology – possible reasons for falling ill

People need to know the primary reason for falling ill in order to rebalance their physical condition and rid themselves of the ‘unwelcome stranger’. This kind of reasoning, again, has its roots in history and therefore it is interesting to compare folk medical explanations with modern cancer aetiologies. It appears that if we exclude the ‘unclear’ category, there are only two common categories: *natural/external* and *natural/internal*, whereas the *psychological* and *behaviouristic* illness explanations represent more the modern way of thinking, affected by evidence or psychological discipline and various neo-religious ideas. It is worth emphasising here that all the categories are to some extent affected by a common idea of personal guilt as being responsible for falling ill (Harjula

1986, 115–135). Therefore, all illness causes become better comprehensible when observed in the context of personal life.

According to the official suggestion of the Finnish Cancer Association, cancer may be caused by inner problems, environmental influences or individual lifestyle. Accordingly, among the preventative suggestions we find advice that one should take care of one's health by practising sports, avoiding the sun, eating healthy food, minimising alcohol intake and checking one's physical condition regularly. The American anthropologist Cecil Helman has proposed that personal explanatory models are marshalled in response to a particular episode of illness, and are not identical to the general beliefs about illness held by a particular society (Helman 2000, 85). Indeed, in their writing, cancer patients use culturally accepted knowledge and interpret it to suit the circumstances of their personal cancer experience. The main problem is that individual experiences, in many ways different from culturally agreed expectations, impact only on the reasoning of a particular person. Consequently, as cancer suddenly becomes an individual challenge, people find it difficult to accept that, despite all individual efforts, they have still fallen ill:

*Usein sairauteni aikana pohdiskelin mieheni kanssa, miten oli mahdollista, että juuri minä sairastuin syöpään. Suvussani ei ollut siihen rasitteita, olin aina ollut laihansorttinen, en tupakoinut ja koko lapsuuteni ja nuoruuteni olin harrastanut urheilua. Yleisurheilua, hiihtoa, palloilua – vieläpä ikäihmisenä osallistuin työpaikka-urheiluunkin. During the times of my illness I often discussed with my husband the reasons for falling ill. How come I fell ill with cancer? In my family there are no traces of cancer, I had always been kind of thin, I did not smoke and I had practised sports my entire childhood and youth. Light athletics, skiing, ball games – even as an adult I took part in sporting activities organised at my work place. (290)*

*En itkenyt, en huutanut, en särkenyt astioita. Mieleeni tuli sen sijaan juttu, jonka olin jokin aika sitten lukenut jostakin lehdestä. Juttu kertoi suurin piirtein näin: “Kieltenopettajat sairastuvat syöpään todennäköisemmin kuin liikunnanopettajat.” Mutta sairastunut olinkin minä! Minä, joka liikuin ja liikutin muitakin päivät ja illat. Minä, joka en laittanut rasvaa leivän päälle ja söin terveellisesti vihanneksia ja hedelmiä. Minä, josta ihmiset ihmettelivät, kuinka jaksan aina olla niin iloinen ja liikkua niin paljon ja että eikö minua koskaan tympäise vielä koulun jälkeen lähteä pitämään jumppaa ympäri kyliä. Ei! Minua ei todellakaan tympäissyt lähteä ja sanoinkin, että sen takia minuun eivät taudit iskee, kun liikun niin paljon. Geenit – geeneissä se vika on. Ei ole muuta mahdollisuutta.*

I did not cry, I did not scream, I did not break dishes. Instead I remembered reading a story from a newspaper. The story went like this: Language teachers have a greater potential to fall ill with cancer than the gym teachers. But I had fallen ill! I had been working out day and night. I did not put fat on my bread and ate healthy vegetables and fruits. Everybody had wondered how I could be so happy and do so much exercise, even after school was over I did not hesitate to give lessons around the village. I was always willing to go and I even told others that I stay healthy because I exercise so much. Genes – there is the problem. There is no other possibility. (121)

These examples demonstrate the need to find the causes of illness. With regard to the course of a person's life, the meaning of cancer can change several times. After falling ill, and during the illness, patients constantly experience new aspects of cancer. During this process many culturally accepted ideas prove wrong compared to individual experience, and thus people negotiate their own illness model based on their own life stories.

Culturally accepted ideas are less flexible, and thus popular cancer discourse stays unchanged. This kind of stability is characteristic to any set of popular beliefs and is connected with the process of communication. When individual experience (personal voice) is in opposition to popular reasoning, communicative acts such as composing a narrative, force people to maintain the culturally pre-set beliefs framing the discourse. Thus, when debating the origin of illness, or other illness-related beliefs, respondents in fact repeat culturally accepted beliefs and thus reproduced them in their narratives. Therefore, I suggest that even if marshalling individual explanations towards culturally approved explanations, all respondents actually select an aetiology appropriate and acceptable within their own life from among the existing explanations.

## **Natural external and internal causes**

The *natural/external* category includes dangers from the environment that influence people's health by attacking from outside. This category is foremost connected with political and economic decisions made in past decades affect the Earth and its ecosystems (see articles in RACHEL Environment & Health Weekly; see also *Rachel's Daughters* 1997, a movie by Nancy Evans). Among the explanations we find polluted air, sunlight, tanning beds, radiation, underground streams, clothes, cosmetics, and also genes and



viruses. In the beginning it is perhaps difficult to understand how these very different factors may belong to one category. Therefore I once more point out that my aim is to track popular reasoning from an ethnomedical perspective. As I go through these explanations, I compare these ideas with thoughts deriving from folk medicine presented in the previous chapter. This is to point out the major changes affecting popular ideas about cancer's origin and the changes in these ideas over time.

The 'bad air' or miasmatic explanation (for example wind from the north, poisonous air from the swamps, etc.) belongs among the most ancient illness explanations (Porter 1999, 10). With modern cancer aetiology bad air refers to polluted city air (246, 381, 512), radioactive tests, the Novaja Zemlja (1961) nuclear detonation and the Chernobyl (1986) nuclear catastrophe, chemicals used in agriculture and the building industry (11, 54, 43, 103, 196, 197, 256, 542). Associating the origin of cancer with bad air is a new phenomenon and therefore needs to be explained here. If polluted city air and the use of chemicals are the results of modern life, cigarette smoke helps to exemplify the diachronic change of popular thought rather well. In folk medicine, tobacco and tobacco smoke have been used to soothe pain and as part of various remedies. The ongoing work on the negative effects of smoke and smoking has caused a change in popular reasoning, so that today cigarette smoke is one of the best known causes of (lung) cancer (2, 24, 28, 51, 86, 224, 236, 265, etc.). According to respondents' explanations, pollution substances responsible for cancer may also be hidden in badly fitting clothes (tight jeans and restrictive underwear, 190) or man made materials (197), and also in cosmetics and similar products (such as deodorants, 229). In this sense culture-based illness aetiologies have not changed, although the substances have. People still tend to believe that illnesses are transmitted within mediating agents.

With regard to harmful substances, several changes in cancer patients' reasoning are fascinating to follow. For example, according to ethnomedical records, fire could be interpreted as a cause of cancer, while today fire is replaced by sunlight or the solarium (38, 56, 559), although perhaps X-ray treatments (337, 512) and electricity cables close to the household (45, 572) may also be interpreted in ethnomedical terms as the modern version of 'endangering fire'.

The belief that earth is responsible for falling ill seems to be entirely forgotten, at least when it comes to touching, sitting on or walking over the ground. This appears to be a more general trend, which may be explained by the fact that modern Finns do not normally have such a close relationship with the ground as rural Finns did, and thus the dangers

coming from touching earth are simply irrelevant (Kivari 2008b). On the other hand, underground streams (185) being responsible for cancer certainly belongs to the category of 'harmful earth' energies. It is interesting to note that these streams were also recognised among German cancer patients as a reason for falling ill (Schwibbe 1989, 51–52).

Perhaps the most fascinating question concerns what happened to the disease worm image. I would suggest that this has been replaced, because of the development of medical awareness, by viruses and bacteria (38). A similar phenomenon has taken place in dentistry, where disease worms causing pain have been replaced in modern Finnish folklore by *hammaspeikko* (lit: 'dental troll') bacteria in both child and adult imaginations (Pekkola 2010). In a similar way to the disease worm image, viruses represent living beings that attack from outside and cause illness.

Unfortunately, there is no real certainty as to what kind of images modern gene theories have evoked in human minds, although despite this genes too are now 'accused' of responsibility for cancer (see 96, 121, 179, 401, 412, 462, 600, etc.). In the ethnomedical sense popular gene theories could be interpreted as modern constructions of illnesses caused by dead ancestors, which has been a very common illness explanation in Finnish folk medicine (Waronen 1898, 17). However, as interesting an idea this is, investigation and proof must be undertaken by another researcher as the emphasis of this thesis lies elsewhere.

The *natural/external* explanation for cancer entails it being seen as a contagious illness (31, 33, 76, 79, 157, 160, 164, 205, 401, etc.). This does not mean that people believe that they have caught cancer from someone else, rather that this view refers more to the social fear of others: *Tunsin olevan leimattu, kuin raamatun spitaaliset*, "I felt myself labelled as the leprosy patients in the Bible." (646). From the pathographies it is apparent that people continuously sense that those without cancer are afraid of them and wish to keep their distance. In the cancer patients' narratives, the idea that cancer is contagious represents a common-sense explanation and is strongly connected with the idea of being labelled by cancer. From the ethnomedical point of view this kind of control is foremost connected to the culturally approved attempts to 'protect' healthy society members (Honko 1960, 57–61).

Dominant among the *natural/internal* explanations are various rational causes dependant on the body possibly becoming more responsive to cancer. We can see some interesting differences when compared with rational illness causes extant in other folk medical systems. The period of modernisation and the construction of the welfare state

signified big changes in hygiene in Finnish homes (Helén & Jauho 2003, 24). In addition, bad clothing – according to modern folklore – or its lack, is no longer an issue, but rather more likely is the quality of clothes, as mentioned above. Other universal health issues, such as food intake, alcohol abuse and smoking habits have continued to be problematic in Finland. As these themes are continuously discussed in public, people are aware of the risks that unhealthy eating, drinking or smoking may bring, although respondents to the writing competition seem to deny that they have been eating unhealthily or drinking too much. In my opinion, this denial could above all be explained by the average educational or professional level of participants.

Unlike eating or drinking, all respondents to the writing competition accepted that smoking is a dominant cancer cause. Lifelong smokers admit that their cancer could be a result of this habit, as do passive smokers:

*Syön paljon vihanneksiä. Kalaa kerran viikossa, lihaa ei tuolloin oikeastaan ei koskaan. Aamuisin juon aina itse-puristettua greippi-appelisiini-sitruunamehua. Elin niin terveellisesti kuin saatin. Tupakka en ole koskaan polttanut, mutta olen kyllä joutunut passiivisen polttajaan asemaan sekä työpaikalla että sairaalassa viedessäni miestäni tupakkahuoneeseen.*

I eat lots of vegetables. Fish once a week, at that time I ate almost no meat. In the morning I always drank homemade grapefruit-orange-lemon juice. I lived as healthily as I could. I have never smoked, but I have been in the position of passive smoker, both at work as well as in the hospital when taking my husband to the smoking room. (024)

At first glance the habit of drinking coffee (28, 543, 572) could be classified as a modern health concern, in the same way that tobacco was said to have positive affects on health in the past. However, the difference is that drinking too much coffee has never been seen as a healthy habit. At least in the Finland the negative affects of coffee overuse were discussed rather early (see for example Waerland 1949, 82). Compared to smoking, which was considered healthy in folk medicine, the bad feeling caused by too much coffee was perhaps more graspable (immediate impact) than the possible harm caused by smoke (slow impact), which in the very short term was soothing to nerves and reduced pain. Despite information regarding the negative impact of coffee, people cannot stop drinking it because it brings joy, and also because drinking coffee is one of the most important social activities among Finns:

*Mutta elintavat... Olen aina ollut huono huolehtimaan terveydestäni, ennen vitamiineihin ja hivenaineisiin tutustumista. En kovinkaan paljon piitannut liikunnasta. Söin todella huolettomasti, useimmiten korvasin lounaan kahvilla ja leivoksella. Olin oikea kahviratti. Siihen saakka, kunnes hivenainelääkäri kertoi, että kahvi sisältää tuhat erilaista myrkkyä ja rientää viidessä minuutissa nauttimisesta rintarauhaisia ärsyttämään. Olisiko siis kahvi kaiken pahan alku ja juuri? Kahvista en kuitenkaan ole vielä kukaan kokonaan osannut luopua. Jotain nautintoja täytyy sentään itselleni sallia! Muuten on taas jo lähellä sairastuminen – askeettisesta ikävästä elämästä johtuen!*

What about my habits... I had always been bad in taking care of my health before I learned about vitamins and minerals. I did not like to do much exercise. I ate carelessly, often replaced lunch with coffee and cake. I was a true coffee addict. At least as long as the mineral doctor told me that coffee contains thousands of different poisons and five minutes after enjoying it goes to annoy glands in the breast. Could coffee be the grounds for and root of all that bad? However, I have not given up coffee entirely. Some kind of joy one has to allow to oneself! Otherwise one would be again close to falling ill – caused by an ascetic and boring life! (572)

If the other causes of illness mentioned in the *natural/internal* category are connected with serious illnesses in general, then the idea that cancer is the result of vitamin and mineral deficiency (288, 290) highlights the new trend in alternative and complementary medicine. According to the cancer narratives, this trend was introduced to Finnish cancer patients in the 1980s and is also present in modern cancer discourse. The second cause connected with (bio)medical discourse on cancer is the use of oestrogen or other hormonal treatments among menopausal women. Respondents (9, 130, 214) believe, or at least suspect, that their illness could be somehow connected with consuming medicine prescribed by doctors.

In a similar way to other rational reasons, losing or gaining weight has for a long time been thought to show underlying symptoms that might raise health concerns. This has gained a new meaning because people are now concerned about their weight mainly because of the culturally agreed norms that guide us towards the modern version of the aesthetic body (Kinnunen 2008, 307–321). This means that some people use lots of energy to control their bodies, while at the same time consuming a great deal of unhealthy food, whereas others stop eating for periods in an attempt to balance their health, sometimes putting the body under great stress (Puuronen 2004, 80–83). Within the modern body-conscious cultural context one should bear in mind that in cases where respondents wrote

that they have always been overweight, this foremost refers to their subjective body image, built on the (perceived) expectations of society.

Following on from this, other societal expectations are also detectable in modern cancer aetiology. Unlike hurting oneself (25, 53, 461, 538, 555, 572, 604) or getting cold (508, 524, 604), some of the causes are obviously sensed as tools of soci(et)al control. Having children too young (277), having too many children (2, 133), or none at all (177, 250, 292, 318, 412) represent individual risk behaviours, which from the societal point of view could be taken as problematic. Having too many one night stands (511) is also interpretable as acting against societal expectations, and in doing so weakening the human body and its resistance abilities (331). The fact that people connect the origin of their cancer with these particular issues demonstrates that they are well aware that acting against socially set norms (normal behaviour) brings punishment, and that the punishment may occur in the form of illness.

These beliefs are also interpreted the other way around, which for cancer prevention work is even more significant. Folk beliefs that, for example, young mothers or women without menstruation do not get cancer, stop people going to a doctor and receiving the right diagnosis when the first signs of illness occur:

*Vihdoin suustani tulivat sanat: "Oliko se sitten syöpää?" Olinhan minä sen koko ajan tiennyt, mutta olin sen niin onnistuneesti sulkenut ulos ajatuksistani. Miten vastenmielinen sana tuo syöpä oli juuri minun kohdallani. Kyllähän jollain vanhalla ihmisellä voi syöpä olla, mutta että minulla, nuorella naisella – minullahan oli vielä niin pienet lapsetkin – minunhan pitäisi olla vahva ja suojella lapsiani. Lääkäri vastasi, että syöpähän se oli.*

Finally, words came out of my mouth: "Is it a cancer?" Well, I had known it all the time, but I had succeeded in closing it out of my mind. How disgusting was the word cancer. An old person can have cancer, but I, a young woman – my children were still so young – I should be strong and protect my children. The doctor answered that cancer it was. (088)

Above all, the natural explanations listed above should be interpreted and understood as internal or external causes which, according to popular knowledge, 'trigger' cancer. Even those respondents who argued that no one really knows what actually causes cancer (see also Schwibbe 1989, 51), believe that certain 'triggers' set off cancer at particular times in a person's life. Therefore *natural/internal* and *natural/external* causes may be interpreted

as ‘triggers’ that break through the individual’s immune system, allowing cancer the opportunity to gain control over the body.

The process of searching for appropriate coping methods is foremost psychological. As an important part of the inner negotiation process, it forms one of the most central issues in cancer narratives. Accordingly, sufferers carefully examine their life history in order to detect the possible reasons for falling ill. During this process the respondents used multiple methods of self examination. They look for psychosomatic and external influences and employ other culturally accepted explanations, such as punishment, contagion or genetics. This kind of culturally shared approach to individual illness represents, in fact, an ancient mythical thought: in order to cope with one’s illness and aim for a successful cure, one must be aware of what possibly caused the illness.

## **Psychological and behaviouristic causes: downtrodden women and ‘go-getter’ men**

In a similar way to natural illness causes, psychological and behaviouristic illness causes also mediate the expectations and concerns of society. In addition, it is also noticeable that in the Finnish context these particular illness causes are very much affected by ideas deriving from health psychology, and are affected by new religious movements such as Buddhism (60, *paha karma*, bad karma) and other mind and body maintenance techniques. As expected, the individual, with his or her characteristics, daily struggles and unsolved problems can be placed at the centre of this nexus. However, the modern setting is to some extent different from the times when folk medicine represented the dominant healing discourse for Finns. An illustration of how that change is important comes from the fact that illness is no longer diagnosed and treated in the domestic sphere. As I pointed out above, modern doctors and patients do not share illness meanings based on sense experiences. By which I mean that when entering hospital, individual work pressures (15, 100, 232, 233, 265, 331, 339, 423, 441, 543, 566, 648, etc.), marriage crises (46, 227, 334, 421, 566, etc.), loss of a relative, sorrow and grief (188, 373, 375, 545, 596, 612, etc.) as well as financial problems (233, 543, 573) must be left behind, as the individual’s daily troubles are excluded from biomedical treatments; even hospital psychologists tend to overlook these concerns (Crossley 2008, 21). When compared to the modern medical

paradigm, this kind of personal concern was more to the fore in folk medicine when negotiating the illness origin and aiming for recovery.

When introducing the behaviouristic and psychological causes of cancer I decided to concentrate on two types of descriptions, which, within the context of the cancer narratives, could be called short psychohistories. The first kind of psychohistory mediates the belief that some people have a *syöpäpersoonaa* (cancer personality) or that they are a *syöpätyyppi* (cancer type). The latter suggests a possible connection between cancer and something that could be described as the *menevä* ('go-getter') lifestyle. These ideas should by no means be separated from each other. These ideas are intimately connected to individual behaviour, ways of thinking and everyday action, and therefore the available written illness reconstructions contain a large amount of individual variation (see also Siikala 1991, 80–86).

The cancer personality concept stems from the culture-bound idea that cancer is the result of certain kinds of individual (mis)behaviour. According to this, people are made responsible for falling ill, either by acting or thinking in an improper manner (79, 87, 195, 339, 475, 533, 563, etc.). This kind of evaluation is again based on the culture-bound expectations that form the setting in which 'normal' is formed of culturally agreed behaviour and thinking. Finns describe an individual with a cancer personality as a person who denies individual desires and puts others ahead of him- or herself:

*Kun oikein ajattelen, niin olen juuri tuollainen tavallinen syöpätyyppi. Aina valmis joka paikkaan ja usein tekemään enempi kuin tahdon jaksaa. Heikko itsetunto ja omantunnontuskia poteva.*

If I think about it, I am exactly this kind of ordinary cancer type. Always ready to participate and make more than one actually can. With low self-esteem, and suffering from poor self-image. (031)

The cancer personality explanation is foremost based on the idea that cancer is triggered by particular psychosomatic conditions, which are additionally influenced by multiple external challenges such as being a single mother (573) or an old maid (140, 177). Respondents also write about the common belief that negative thoughts (33), a pessimistic nature (409) or self-destructive ideas (289) can be interpreted as causes of cancer. Of course, in cancer narratives these causes become interpreted and represented in numerous ways. Adopting these culture-bound explanations may even lead to self-accusation:

*Sitten aloin miettiä mikä oli saanu kyhmyn muuttumaan. Mitä mä olin syönyt tai juonut väärää? Milloin muutos oli alkanut tapahtua? Oliko remontin aineksissa ja työssä jotain herkistävää ja rasittavaa? Onks mun mieleni saanu tän aikaan? Mähän olen tällanen helposti masentuva, yksinäinen murehtia , joka muutenkin hautoo synkkiä ajatuksia. Ja kuinka pitkälle taas tänkin masennuksen juuret ja syyt johtaa.*

I began to think about what had made the bump change. Did I eat or drink anything wrong? When did this change begin? Was there anything in the materials I used when renovating that I was allergic to, or something exhausting about my work? Has my mind caused it? I am this kind of person who is easily depressed and worries alone as a matter of fact, dealing with dark thoughts all the time. And how far away actually are the roots of this depression. (087)

People find it annoying that the cause of their illness is often seen as personal misbehaviour. On the other hand, by putting these beliefs on paper they perpetuate them, even though their primary intention is to deny these ideas:

*Mieleeni tuli kysymys, olenko itse hankkinut tämän sairauden. Joku oli aikoinaan sanonut, että elämäni on itsetuhokäyttämistä. Elämänrytmilläni tuhoan elämäni. Nyt oli käynyt näin! Mutta torjuin itsesyytökset: kaikki se, mitä olin kokenut, miten olin elänyt, oli ollut rikasta elämää. Juuri niin minun oli pitänyt elää, saadakseni kokea sellaista elämän rikkautta. /---/ Olinhan saanut kokea melkein kaiken sen hyvän, mitä elämä voi antaa. En voinut syyttää itseäni, en katua elämäntapaani.*

I asked in my mind if I am personally responsible for this illness. Someone had once said that my life is a self-destruction. That with my life rhythm I destroy it. Now it has happened! But I denied all self-accusations: all that I had experienced, how I had lived, had a rich life. That was exactly the way I had to live my life to experience all this richness of life. /---/ I had experienced all the good things life can give. I could not blame myself, or regret my lifestyle. (160)

Comparing female and male stories reveals an interesting split between the sexes' attitudes on the idea of the cancer personality. Namely, female respondents seemed to adopt popular explanations about depressive personalities as the cause of cancer more frequently than male. Male cancer patients claimed that the reasons for falling ill are connected with their nature and behaviour as *menevä mies*, which can be translated into English as 'go-getter'. This gendered difference made me pose two questions: firstly, what



meaning does *menevä mies* have in Finnish language and culture, and secondly, does the use of such a concept affect cancer patients' illness experiences? The second question was, again, inspired by Arthur Kleinman's statement that finding a proper explanation for falling ill may be seen as the first step towards coping with illness (Kleinman 1980, 104).

The available materials gathered via the writing competition contained numerous responses from breast and gynaecological cancer patients, and this suggested an examination of the ideas of prostate cancer patients in order to find answers to my questions (037, 173, 220, 346, 403, 501, 508, 534, 562, 669; see also 110, 157, 305, 406, 470, 509, 569), although, the concept of *menevä mies* is also used by other male respondents and in writing *about* male cancer patients. Unfortunately, the narratives collected in 1994 demonstrated that it was difficult for men to discuss their prostate cancer openly as it was perceived to be an embarrassing topic (see also Chapple & Ziebland 2002, 826–827):

*Mutta mikä on syövässä sellaista, että sitä on vaikeampi tunnustaa kuin esimerkiksi sydänvikaa, mahahaavaa tai vaikkapa eturauhasvaivaa. Syöpä on kuin mielisairaus, sukupuolitauti tms, joka pyritään salamaan, vaikka siitä paranisikin lopullisesti, kuten minun kohdallani nyt on käynyt. Ei ole syytä ylpeillä tai leikkiä sankaria, vaikka voittaa näin vaikean sairauden.*

What is it with cancer that it is more difficult to admit than for example heart failure, a peptic ulcer or even problems with the prostate? Cancer is like a mental illness, a sexually transmitted disease, etc., which everyone tries to hide, even if one could be healed from it, as has happened to me. There is no reason to be proud or play the hero, even if one conquers such a difficult illness. (650)

In order to gain more evidence on the subject, it was necessary to search for answers in Internet forums that cater for cancer patients. Comparisons between the written cancer narratives and current discussions in these forums showed that today, instead of hiding their illness, men have found ways to discuss their illness experience more openly. In comparison with 1994, public discussion about prostate cancer has become a daily subject in the Finnish media. Cancer support organisations organise public meetings in which various issues relating to prostate cancer, such as testing, screening and treatment, are openly discussed. However, it is not clear how openly men discuss their illness with their families, friends or colleagues, as having cancer still carries a strong culture-bound stigma to which men may be more susceptible than women.

To begin with, I questioned my Finnish colleagues and friends to clarify the meaning of *menevä mies* in cancer discourse. Here are some of their spontaneous answers:

- an active man, who is not mouldering at home. Has some negative connotations relating to activities connected with bars and females;
- it has many meanings depending on context. It can mean a sporty or active man, the wife may nag that her husband is never at home and is thus a *menevä mies*, it may refer to someone who feels good in bars, as well as having some connotations about sexuality, although the latter is however not so important;
- I just asked around here and it seems that most people interpret it as something positive, e.g. active, business oriented, ready to participate in different things;
- regarding illness, *menevä mies* may refer to the fact that the man has not been concerned about living healthily, but has “burnt the candle at both ends”. Not necessarily sexual;
- yes, not sexual, but a flirting man may also be a *menevä mies*.

Accordingly, the *menevä mies* concept includes a socially active man who does not take care of his health. The concept is mainly regarded as positive. The negative connotations relate to social activities associated with spending time in bars and coming into contact with numerous women. However, *menevä mies* does not necessarily refer to someone who is sexually active. These explanations are required mainly to understand the following discussion about the idea of the go-getter lifestyle as a trigger for prostate cancer.

As the next step, I introduced a statement and question for discussion in the cancer patients’ forum in the *miesten syövät* (male cancers) section, as follows:

“Many people argue that cancer is a result of a particular personality. I have heard that prostate cancer is recognised as an illness of the *menevä mies*. What does this actually mean?”

The first answer I received was that this is *huuhaa* (‘total crap’), similar to the belief that cancer is result of a sinful life. Although the answer was not polite, I was really glad to receive it because respondents discussed the connection between cancer and ‘sinful life’ rather often in the cancer narratives. In several answers people referred to nonexistent medical evidence in this connection. This kind of attitude towards the origin of cancer was no surprise to me. I have followed Internet discussions for several years and, if religion-

based discussions are excluded, it is rare for someone to dare to discuss something that could be interpreted as alternative or non-scientific. Whereas the cancer patients' narratives that I analysed offer ethnographic insights into the popular reasoning on cancer, the cancer forum deals with cancer patients' acute issues, such as the meaning of a diagnosis or the effect of a medicine. In the Internet forum, people also share the newest evidence-based medical results and discoveries on cancer. This is because the forum discussion is supported and moderated by cancer support organisations representing scientific medical discourse. Thus, the Internet forum is more for discussing cancer according to the medically proven paradigm.

One man wrote that he had met some men who have prostate cancer and based on this "evidence" he suggested that there were all kinds of men with different lifestyles among them. However, he noted that perhaps those men with so-called 'go-getter' lifestyles are otherwise more open too, and talk about their problems in public more easily.

With Finnish men, this concept refers to something that again becomes understandable in the broader socio-historical and cultural context. If female cancer patients claim that cancer is a result of underestimating themselves and suppressing individual desires and needs, then in male cancer patients' stories overestimating individual power and state of health becomes dominant. The *menevä mies* concept, with its positive and negative connotations, also implies risk behaviour because, within this paradigm, men do not care for or pay attention to their health. It mediates the (desired) active male role in society as well as the insignificance of an individual's health for those who exploit this role. And when illness occurs, using the concept of *menevä mies* is a culturally acceptable way to search for salvation and cope with the situation.

With this selection, I wished to demonstrate that according to popular cancer aetiology, depression and optimism may equally lead to falling ill with cancer, which again proves the unpredictable nature of this illness. The folk beliefs about cancer that are represented in the cancer narratives, above all mediate that health and illness are affected by biological, ecological, behaviouristic and social conditions, all of which affect the individual. Accordingly, psyche cannot be separated from soma (Dalton et al. 2002, 1 322). Because of culture-bound reasoning, people are aware of various illness causes typical to cancer, but while mentally negotiating these causes they merge the causes with their own lifestories and thus some of the reasons gain more significance than others. When dealing with narrative self-expression, an individual's expressive skills, and particularly the

selected narrative tendencies, should not be overlooked in order to understand what is going on.

## **The vulnerable position of the cancer patient**

As people communicate on health issues, they share their culture-bound ideas. These ideas are examined critically and not necessarily held to be true. However, it is important to keep in mind that all kinds of conversations (including inner dialogues) are connected to our culture. Therefore it is important to be aware of the culturally adopted health beliefs and communications that mediate and represent culture-bound understanding. Where social constraints are set on a particular discourse, as appears to be the case with cancer (Lepore & Revenson 2007, 313–314), ideas expressed in writing become even more significant. Above all, comprehension of such culturally pre-set expectations helps us understand and interpret the individual challenges that face people with cancer.

Before falling ill, people admit to being afraid of cancer (38, 102, 335, 350). However, the cancer diagnosis places people in an entirely new situation. From an individual point of view this means that people realise their lives are suddenly endangered. For individuals, having cancer means that a human being will be placed in a different time and space dimension, which British journalist Susan Sontag has described as falling out of this world, that is to say “emigrating the kingdom of well” (Sontag 1978, 3). Having cancer also means that the illness experience divides the individual life course in two: before and after, although such division is possible only in event-based interpretations, such as narrative self-expression. The changed situation signifies the beginning of a process that has a lot to do with identity alteration: losing and finding oneself.

Loss of self happens quickly as people are pushed outside their daily routines. The ability to go to work and carry out one’s daily duties is particularly understood as the symbol of a functioning human being. The ability to work should be understood as an important part of personal identity. For many people, particularly in urban areas, the workplace and work colleagues represent the most important social networks. Additionally, work assures the earnings necessary to manage everyday money matters on a social level. Without the ability to work, people feel isolated. This means that in addition to the physical concerns, serious illness also causes people to be confronted with economic

and social problems that exclude them even further from 'normal' life, leading to psychological challenges (Hayes & Nutman 1981, 14).

Illness changes not only the individual's position in society, but also his or her surroundings. Family members, friends and work colleagues are equally confused when unexpected illness strikes. For many, this means that they do not know how to behave or what to say. Quite often such uncertainty is based on culture-bound fears and erroneous beliefs. In such situations people in the social circle around a cancer sufferer often decide to avoid the subject, or even the person, which again affects the person's condition in a negative way:

*Kyllä ihmisten kohtaaminen kumminkin muuttui, tilanne oli joidenkin kohdalla samanlainen, kun kuoleman kohdanut ihmisen lähestyminen on joillekin, minullekin vaikeaa. Ystävät kyselivät vointia, ottivat ja elivät mukana, lohduttivat, mutta toiset pelkäsivät minua, ja sen havaitseminen oli minulle vaikeaa.*

Seeing people was different [in comparison with before]. Some acted as before, for others, also for me, it was difficult to see someone who had faced death. Friends asked how I felt, and sympathised with me, but others were afraid of me and this was hard to handle. (015)

*En oikein tiedä mitä olisin halunnut heidän sanovan; kaikki saamani myötätunnon osoitukset kolkuttivat omaatuntoani, ja hiljaisuus ja välinpitämättömyys loukkasivat. Paras oli varmaankin se, kun he kysyivät, että miten itse suhtaudut asiaan. Tätä kautta pystyin puhumaan omista tuntemuksista heille ilman huonoa omaa tuntoa.*

I do not really know what I expected them to tell me; all condolences I received made me self-conscious, and silence and ignorance did hurt. The best was perhaps when they asked what I thought about it. In this way, I could share my feelings without becoming self-conscious. (531)

The popular image of cancer is closely connected with death and dying, and thus, often at the societal level, people with cancer are treated as 'fading'. This particular image of cancer influences expectations of the cancer patient's behaviour. According to culturally accepted ideas, people with cancer are expected to pass away shortly after the cancer is discovered. Thus, those with the disease are expected to act and look differently to 'normal' people. Indeed, social expectation of illness behaviour encompasses even the patient's appearance. If a person looks too good, society may refuse to believe that he or

she is suffering from cancer. According to societal expectations, cancer patients should behave like dying people and therefore be excluded from daily activities: they should not work, they should not enjoy life or follow the daily news. Taking part in activities considered inappropriate for cancer patients might even insult others – those who are ‘normal’:

*Olin jossain tilaisuudessa, kuulin keskustelun eräästä henkilöstä, joka oli tanssimassa “tuokin on täällä tanssimassa vaikka sairastaa syöpää?!” Silloin olin vähällä mennä heiltä kysymään “miksi ei saisi olla pelkäättkö että tarttuu? En voinut mennä, sillä olin niin loukkaantunut sen henkilön puolesta vaikka en häntä tuntenutkaan lähemmin, tiesin kyllä että hän todella on samassa “veneessä” kuin minäkin, sillä kai se kosketi niin läheisesti – silloin vaikka joku sanoo ymmärtävänsä miltä tuntuu sairastua syöpään – uskallan väittää, vain hän tietää, kuka tämän sairauden uhri on, että miltä se todella tuntuu!!*

At one party I heard a discussion about someone [with cancer] who was dancing. “Look, even this one is dancing?!” I was about to go and ask: “Why shouldn’t she, are you afraid that you’ll catch it?” I could not go because I was so hurt, even though I did not know her personally. I knew that we were in the same boat, perhaps that’s why it hurt me so badly – even if someone tells me he or she understands what it feels like to have cancer, I dare to claim that only victims of that illness know how it really feels!! (240)

It appears that when a person announces that he or she has cancer, society begins a process of management relating to the sufferer’s behaviour and appearance. Conclusions, as well as (mis)judgements, are made according to each individual’s understanding as outlined by culture-bound ideas relating to the particular situation. If the sufferer acts ‘unnaturally’, by not following cultural norms appropriate for cancer patients, ‘normal people’ feel threatened. Sometimes the popular image of cancer affects behaviour so intensely that some people still do not hesitate to break their social connections with those who have cancer:

*Pääsin takaisin työelämään. Olin ollut työtehtävissä, jossa jouduin koskettelemaan asiakkaitani! Oli hoitotyössä. Olin avoin ja kerroin syöpäleikkauksestani! Jotkut suhtautuivat asiallisesti, mutta monet hyvin ennakkoluuloisesti ja pelko paljastui erään asiakkaan sanoessa: “Syöpähän tarttuu, en sitten tule enää hoitoon!” En tiennyt, että*

*näin voimakasta ennakkoluuloa on vieläkin! Oli muitakin, jotka jättivät tulematta luokseni pelon tähden! Syöpä – ruttotauti! Voi, miksi en osannut pitää suutani kiinni!*

I was back at work. Because of the nature of my work [massage], I had to touch customers! I was a nurse. I was open and told them about my cancer surgery! Some took it calmly, but others had prejudices and were afraid. One customer told me: “Cancer is contagious. I will not come to you anymore!” I did not know that such strong prejudices exist today. There were also others who did not return because they were afraid! Cancer – a plague-disease! Alas, why could I not keep my mouth shut! (079)

It is not unusual that in addition to the patient, community members will also ask: ‘What has she or he done wrong to be punished in this way?’

*Koska paikkakunta oli pieni, missä asuin, tieto sairaudestani pääsi kuitenkin leviämään. Jos missä kuljin, niin ihmiset tulivat puhumaan minulle, että miten se on mahdollista, että sinullekin se voi tulla, koska liikut paljon, et polta, et juo alkoholia jne... Jopa kotiin soiteltiin ja kysyttiin.*

As I lived in a small town, the information about my illness began to spread. Wherever I was people came to talk with me and wonder: How is it possible that you got it, you work out a lot, you don’t smoke, nor do you drink, etc... They even called me at home and asked. (091)

This kind of judgement made on a societal level may, again, cause intolerance towards sufferers. Possible answers to this question are typically found within the individual’s history, as I demonstrated above. In some situations, however, it is difficult to define the faults of the sufferer, and this becomes particularly complicated when the cancer patient happens to be a child or youngster. Consequently, parents or even grandparents may become the stigma carriers as potential norm-breakers:

*Miksi kohtalo on näin epäoikeudenmukainen? Miksi optimistinen ja elämänhaluinen lapsi saa kärsiä? Rakas viaton lapsi. Sairaus on synnin palkka, sanovat jotkut. Rangaistus. Mutta kenen synti on niin paha, että viatonta rangaistaan? Minun vai Paavon vai jo edellisten sukupolvien? Jos kysymys on rikoksesta ja rangaistuksesta, niin mielestäni viattoman lapsen rankaiseminen on rikoksista pahin.*

Why is destiny so unfair? Why must an optimistic and lively child suffer? Dear innocent child. Illness is punishment for sins some people say. A punishment. But whose sin is so bad that the innocent one is punished? Is it mine or my husband’s, or does it come from

previous generations? If the question is about crime and punishment then I think that punishing the innocent child is the worst crime of all. (402)

The dominant beliefs that underline behaviour towards cancer patients on a societal level are firstly, respect paid to the dying (leaving sufferers alone); secondly, the fear of contagious illnesses; and thirdly, avoiding a potential norm-breaker. With these culture-bound ideas in mind, it is worth emphasising that despite continuous social control, the path of illness is very personal. For cancer patients, this generally means an inner challenge hidden from outsiders. In order to accept and correspondingly also to deny the culturally set 'label', people carefully analyse how they have behaved and lived in the past. This inner negotiation process examines the reasons for falling ill, and at the same time helps the sufferer both cope with the idea of being ill and with the search for possible ways out. According to the cancer narratives, such negotiation processes make inner growth possible. After experiencing exclusion from 'normal' life, people realise that, in fact, they are not able to completely control their lives, and accordingly every lived moment becomes more significant than previously.

## Conclusions

In this chapter I have argued that cancer discourse, a culturally complicated phenomenon, is defined by three significant aspects relating to the disease. The first aspect affecting reasoning on cancer is socio-historic development. Accordingly, cancer is identified as an incurable illness causing pain and suffering and leading sooner or later to death. This image derives partly from the folk medical context in which, historically, people were incapable of diagnosing and treating cancer; and partly this view relates to cancer's biologically uncontrollable nature. This second aspect has led in part to the stigmatising image of cancer. An image that is connected with fear and uncertainty and which is shared by all sectors of society. According to popular reasoning, cancer is believed to be contagious. The other equally strong socioculturally agreed belief sees cancer as a punishment for some kind of norm-breaking. The third reason concerns cancer's complex nature as an illness. Cancer has multiple forms and therefore it is difficult to recognise the symptoms, and extremely challenging to propose suitable preventative methods. Thus, for cancer patients, culturally agreed cancer discourse contains numerous possible



interpretations and definitions of the internal and external reasons for the triggering of the illness.

The cancer narratives analysed in this work support Mel Greaves' suggestion about the uniqueness of cancer. Based on these narratives, every single cancer case may be seen as the complex outcome of internal, external, natural, psychological or behaviouristic causes connected with the individual's life. Every time cancer occurs the situation or the setting is new, and therefore the individual's reasoning on possible aetiologies, as presented in the cancer narratives, is full of various illness interpretations. Therefore, to distinguish popular ideas on cancer aetiology is a challenging task. Its complexity lays mainly with respondents' heterogeneous attitudes towards the represented beliefs. In their narratives cancer patients may agree with popular explanations or deny them; however, debating the origin of cancer is a significant theme in cancer patients' writing. Popular reasoning about the onset of cancer also explains why, within the cancer narratives, it is so important for sufferers to find reasons for their illnesses.

In this chapter I have demonstrated that when composing their narratives, the respondents were confronted with culturally pre-set beliefs that frame cancer discourse. In their writing, people explain their illnesses from the personal point of view, taking their personal histories into consideration. After they are diagnosed with cancer they go through a private dialogue involving the socioculturally agreed understandings of the internal and external aspects that might have triggered the cancer. In order to explain the onset of their illness, they search for aetiologies that match their own lives. The most commonly accepted aetiology makes people individually responsible for falling ill. Although many cancer patients do not agree with this assumption in their writing, they point out that cultural uncertainty about cancer's origins labels patients and makes their position particularly vulnerable in everyday life.

## **6 The Moment of Diagnosis and Metaphoric Transformation**

If the pathological drama surrounding cancer may be thought of as a path full of emotion, then there are several reasons why the moment of diagnosis may be considered the most critical point on this path. Most people lack any personal experience of cancer and, therefore, the moment of diagnosis is often one that evokes in the patient the most drastic cultural images. As I pointed out in the previous chapters, these images contain information gained via language, tradition and the everyday communication framed by social and cultural setting. According to popular explanatory models, cancer is imagined as a secretive, evil and dramatic illness, which has achieved the qualities of a modern mythological disease. The material at hand as well as the current discussion forum for Finnish cancer patients demonstrates how people are afraid of cancer because of its unknown origin and direct associations with death.

It is worth emphasising that because of the close connection with death and the lack of accurate scientific clarification of what actually causes it, cancer represents a threat to human existence and therefore the concept of cancer represents a taboo in the individual mind as well as in cultural discourse. Having cancer is still considered an abnormal situation, and is even approached in some cases as a form of deviance. According to current social arrangements, individuals diagnosed with cancer must adopt the role of cancer patient, which separates them from others. For these reasons, the moment of diagnosis represents an event that irrevocably breaks the normal flow of life.

It is important to note that most people who receive a cancer diagnosis find themselves in an entirely new and surprising situation. In many cases the diagnosis of cancer causes people to lose their negotiated identity and their previously established place within society. Using the terms and language of cultural studies, they go through a transformation. In his work concerning stigma and identity, the sociologist Erving Goffman put forward the idea that “the stigmatised individual tends to hold the same beliefs about identity that we [others] do” (Goffman 1963, 7). Although some modern cancer patients refuse to adopt the role of stigmatised cancer patient, despite social expectation (Frank 2000, 135–156), none of them is protected from the shock that follows diagnosis. Thus, Goffman’s statement stands: when the diagnosis of cancer is received, most people identify themselves with reference to the existing cultural understanding as stigmatised cancer

patients. Because of this understanding of cancer as a lethal disease, many people treat the cancer diagnosis as a death sentence. Accordingly, the moment of diagnosis is filled with uncertain inner feelings that are difficult to express (see also Chapter 9).

In this chapter I analyse Finnish cancer patients' writing using their own cancer experiences in order to point out how metaphors and metaphor-like expressions are employed to express cancer patients' inner feelings. I demonstrate the significance of metaphors as a culture-bound key that accurately allows description of the significant transformation that takes place within individuals when they receive the cancer diagnosis. According to the materials analysed, the moment of diagnosis may be interpreted as the most crucial in terms of the cancer experience, which for many patients causes inner chaos and loss of self. In recent discussions, metaphors about illness and health have been interpreted as stigmatising markers in political, social and cultural discourse.

## **The moment of diagnosis and subsequent expression of emotion in writing**

In order to become calm after the discovery of cancer, people must go through various emotions in the attempt to regain their 'original' identity. The philosopher and humanist Georg Henrik von Wright has suggested that with the help of language, people may express, describe and compare their emotions so that others may understand them (von Wright 2001, 595–622). Verbalising the cancer experience is a complicated task for two reasons: firstly, cancer represents a taboo in everyday communication, and secondly, cancer evokes strong emotions. For these reasons, cancer patients must carefully decide on the audience, time and place when expressing their concerns, thoughts and feelings about cancer. Otherwise, as expressed in the pathographies (084, 050, 136, 233, 240, etc.), they might risk losing their work and social position as well as friendships and relationships with colleagues. It is also difficult for family members to discuss cancer, and in cases where the progress of the illness causes physical or psychological issues, patients often prefer to stop discussing it, or even hearing about it. Therefore cancer patients must find and employ other methods of self-expression.

Some discover painting as a form of therapy (Figure 13), others music or reading, but perhaps the most common way to express unspoken issues is through writing. Writing is a possibility for self-expression, which helps to clear the mind and make complicated issues

understandable. In addition, people choose to write instead of speaking because, as cancer patients, they will soon have experiences reinforcing the fact that cancer is a culturally stigmatised issue that should not be discussed in public.



Figure 13. Picture added to a cancer narrative

The moment of diagnosis marks the beginning of an individual's 'cancer path'. According to the descriptions, this particular experience is often sensed as a physical experience, containing vivid images and feelings, which remains beyond the understanding of others. Although many people seem to succeed in staying calm and controlled at the moment of diagnosis, their stories prove that for a while they lose their connection to the outside world. They forget the hospital personnel or other people around them, as well as their sense of reality. As they absorb the diagnosis, they go through a variety of emotions. For example in Seth, Hanna and Ruth's writing, which were presented in Chapter 4 in full length, the moment of diagnosis is described with varying intensity. For Seth and Hanna, the pre-symptomatic period caused health concerns beforehand and thus, for them, the moment of diagnosis has different meaning than for Ruth, who feels herself happy and full of life. For Ruth, as for many other cancer patients without pre-symptomatic issues, it is really difficult to comprehend being diagnosed with an illness that has a lethal image.

After reading numerous accounts I realised that the participants in the competition employed particular words when expressing their emotions and feelings. I noticed that instead of unfolding a set of emotional ups and downs after receiving the diagnoses, many respondents used metaphoric expressions containing various images and feelings. For example, regarding the moment of diagnosis, the expression *pudonnut syvään mustaan kuiluun* (fallen into deep darkness) was repeated so often (027, 031, 041, 067, 089, 106, 332, 482, etc.) that it became repetitious. There were also numerous other metaphoric expressions that were used repeatedly, such as *kuolemanlaakso* (death valley) (031, 106, 155, 204, 243, 419, 436, 451, 463, 476), and also *viimeinen ranta* (last coast) (059) or *lähdön maisema* (take-off landscape) (173). The latter are mainly connected with patients' feelings about death and dying. Thus, not only the moment of diagnosis, but also the patients' ideas regarding death and dying, were often veiled in metaphoric expressions, which demonstrates that culturally marginal situations, thoughts and emotions are expressed using different vocabulary.

As an observer, I could not stop myself asking why people used such fuzzy expressions, rather than using other, better defined, words that would perhaps have been more accurate. At first I suspected that the use of metaphoric expressions contained linguistic or social constraints of some form that forced people to hide their true feelings. After having posed this to my colleagues on several occasions I began to doubt whether this primary assumption was correct. In fact my colleagues from within the field of folklore took a contrary view, pointing out that the use of metaphor should be considered more as a form

of poetic freedom that can describe feelings far more accurately than other forms of description. According to Anna-Leena Siikala, metaphors, words of effect and verbal associations used as individual expressions in narratives “may, because of the unusual nature, draw attention to particular items and thus act as expressions of evaluation” (Siikala 1990b, 23–25). Consequently, the use of language in connection with significant feelings aroused my curiosity and encouraged me to observe and study the use of metaphoric expressions within cancer narratives. During this process my initial assumption about the way metaphors are used in the expression of emotions altered several times, leading to the conclusion that metaphoric expressions have major significance in the communication of personal emotions.

## **Metaphors in health and illness discourse**

The use of metaphors in the discourse on health and illness is not a new topic. Susan Sontag is well known for her criticism of illness metaphors in political and social discourse (Sontag 1978; 1988). Above all, Sontag has pointed out the significance of metaphor in the construction of meaning within illness discourse. Her statement is clear: plague, cancer, AIDS, are names for illnesses which, in their own value-laden and stigmatising way, are used as markers in political, social and cultural discourse.

The folklorist, Mojca Ramšak (2007), has examined the use of metaphors in both cancer patients’ and doctors’ accounts of cancer. Inspired by Sontag’s writing, and Lakoff and Johnson’s work on the significance of metaphors (Lakoff and Johnson 1980; Lakoff 1987), Ramšak exposes numerous “killing metaphors” based on the characteristics of binary opposition present within Western reasoning: everything concerning illness is bad, everything concerning health is good; everything that is up is good, everything that is down is bad (see also Onikki 1992, 33–59). Consequently, Slovenian cancer patients fall into depression as they hear their diagnosis. They are forced down by their illness, or their life becomes “shadowed by darkness”. Cancer marks “the end of the life path” or “the end of the earthly road.” (Ramšak 2007, 23–45). The empirical and cross-cultural study of Ulrich Teucher allows an assumption that similar metaphoric expressions are common to all Western cancer patients (Teucher 2003, 5–9).

In the following model (Figure 14), the most dominant metaphor clusters relating to cancer as a “growth inside”, “intrusion”, “invasion”, “obstacles” or “oppressive

surroundings” are shown in multidimensional structure. The image of cancer as an outside intruder also explains why the treatment process (Figure 15) is most typically regarded by cancer patients as a “battle”, “hope”, “task”, “work”, “race”, or “contingency” (Teucher 2003, 6–8). The same metaphors are used also in Finnish cancer patients’ written narratives.

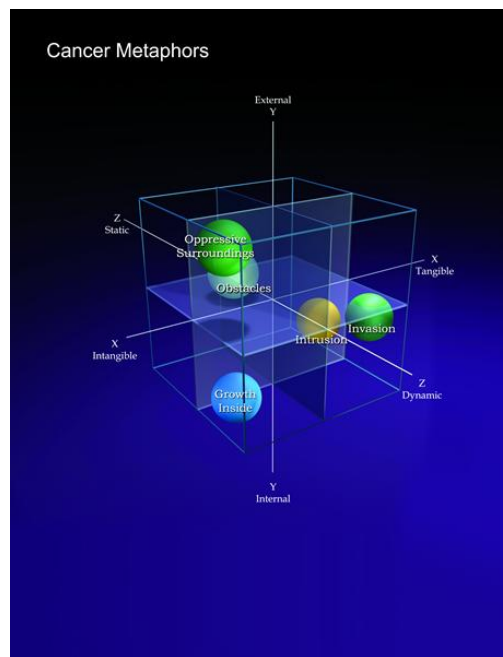


Figure 14. Cancer metaphors (Teucher 2003, 7)

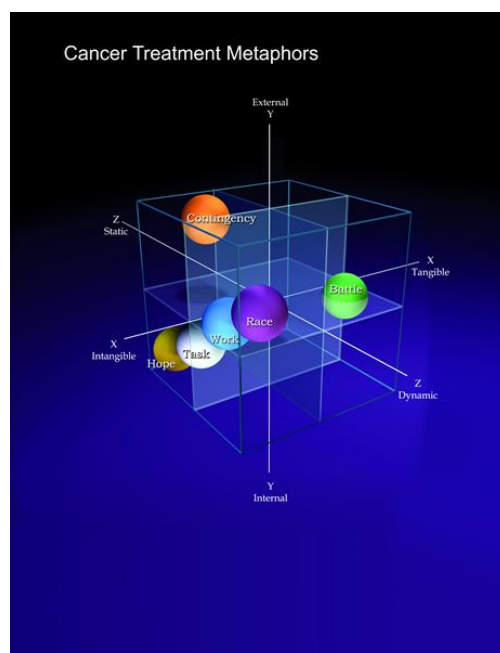


Figure 15. Cancer treatment metaphors (Teucher 2003, 8)

Metaphors relating to health and illness are based on an opposition in which health is presented as the normal condition, and illness as abnormal. Michael Foucault has argued that such binary thinking began to spread in Western medicine as medical science began to distinguish the difference between the normal and pathological condition (Foucault 2006, 40–41). Nevertheless, ethnomedical studies of rural tradition and folk medical thinking demonstrates that folk healers, as well as mainstream doctors, define diseases as different kinds of malevolent force. Falling ill was, and apparently still is, interpreted as a violation of norms, with illness seen as a punishment for transgressive behaviour (Harjula 1986, 15). In a similar way, conventional medicine represents ill health as an abnormal condition that ought to be avoided by all means. There is nothing new about defining illness as a deviance. Thus, falling ill is just another cultural experience mediated by language.

Susan Sontag's followers have claimed that illness metaphors used in political, medical, and social discourse are entirely inexcusable. Illness metaphors, including the word cancer, are interpreted as stigmatising, divisive and politically incorrect. I agree that viewing patients as 'diseased bodies' represents a serious and unfortunate confusion on the part of modern medicine. However, I hope to show that even if we succeed in changing the healthcare system, the way people think and express themselves would remain unchanged, because serious illness is and will be the greatest threat to the human myth of continuous life (Becker 1973, 73).

Ulrich Teucher suggests, somewhat differently, that the texts as metaphor and the metaphors in the texts can reveal a writer's general orientation towards the body and the self, illness, life and death. As such factors and orientations differ, often radically, each cancer narrative tells a distinct story. Moreover, the language of each narrative reveals an astonishing variety of attributed or assumed meanings that appear particularly crucial in cancer. Metaphors that may seem constructive and therapeutic to one patient or writer (or to his or her readers) can be destructive and further traumatising for others. (Teucher 2003, 1–2) Thus, what Teucher says is that it is necessary to analyse the range of metaphoricity in cancer discourse in order to conceptualise cancer within particular linguistic and cultural settings.

Because of my use of a folkloristic approach, my particular interest is somewhat distant from the study of political, medical or social issues relating to health and illness. My primary aim is to comprehend how individuals feel on hearing the word cancer, how they experience the illness process, how they express their experiences and why. This is not a psychological concern, rather it is a desire to present the complexities present when trying



to understand how metaphors work. Using the broadest meaning of cultural studies, in this section I aim to present the way in which metaphors function as ‘picture words’, “in constant interaction with social situation, cultural values, the poetic tradition, and so forth” (Friedrich 1991, 24). In order to illustrate the complexities present in understanding the role of metaphor, I examine how metaphors work and what they do in particular situations. Based on the material at hand I present the metaphoric expression as a valuable linguistic tool used in the sharing of ideas, including those relating to the social transformation, physical suffering and emotional roller coaster that follows the diagnosis of cancer.

## **The meaning of metaphors**

In every language there are numerous words that describe inner feelings. Words like fear, confusion or sadness are foremost culturally agreed markers. Words describing emotions carry certain cultural meanings. The Canadian literary theorist Northrop Frye has said, “what makes a word a word is its difference from other words, and what gives the words a public meaning for a community is the disentangling of them from the associations of those who use them” (Frye 1985, 585). My analysis of cancer narratives illustrates that culturally agreed words describing emotions are not necessarily the best tools with which to describe the personal experience of cancer. Rather, people employ various primary genres, such as narratives, sayings, poems or metaphors, that make their reasoning comprehensible in the cultural context.

Concerning Man, culture and the use of language, various studies have pointed out that our everyday language use is restricted by subconsciously accepted rules and customs that lack rational explanation. For researchers, this above all, means paying careful attention to a community’s sense of self-expression and language-bound ideologies (Hymes 1974, 31). This notion refers again to cultural frameworks placed over our self-expression and argumentation in different contexts, which we must understand if we want to understand the meanings of utterance of any kind. On the other hand, folklorists and anthropologists have demonstrated that people share mythical images which, in oral and literary tradition, as well as in everyday reasoning, may be interpreted as poetic formulae. In fact, poetic self-expression, in a similar way to ethnographic writing, may help to overcome anxiety and fear, and to soothe trauma (Timonen 2004, 307f.). Accordingly, one might suggest that the use of ‘picture words’ during the verbalisation process is a subconscious decision fixed

by a form of linguistic code. It is more challenging to decide whether the code that directs the use of metaphors in texts should be approached as a linguistic restriction or a poetic freedom.

In his study of polytrophy, the anthropologist Paul Friedrich attempts to unite the two opposing approaches (Friedrich 1991, 17–55). Friedrich has proposed that tropes, or ‘extended words’, may express images, modality, formality, contiguity, analogy, vertical analogy, condensation or expansion. According to Friedrich’s assumption, the main task of the metaphoric expression is to mediate the real (external) world (Friedrich 1991, 54–55). The problem with Friedrich’s conclusion is that it is based on a poetic account (literary text) full of figurative speech, while the content and structure of written cancer narratives lies between the oral and written tradition of self-expression, without fulfilling the expectations of folklore or literature (Peltonen 2006, 110–111).

Apparently, the pathographies have qualities of their own. The main task of cancer narratives is to represent the self in various aspects (Hawkins 1999, 10). The respondents do not only mediate the real world, but with the help of selected voicings, they also express multiple images of the self that in various ways relate to cancer. During the composition of thematic narratives, the respondents combine methods of traditional expression (folklore) with elements of literary tradition (literature), making the interpretation process more complex. However, because of their ‘fixed’ written form, cancer patients’ writing may be approached as autonomic discourse.

In Chapter 2 I suggested that the dominant emotions in cancer narratives that follow the development of pathological drama are bound up with the idea of dying, which means that the course of the pathological drama usually consists of phases of shock, denial, anger, trade, depression and acceptance (see Chapter 2). My assumption is that, according to patients’ internal reasoning, these feelings reoccur and become interpreted continuously according to the situation. Continuing on from this, I wish to demonstrate how these feelings become expressed in writing following the structural segments of narrative. To begin and exemplify my analysis in the extended context of secondary narrative I return to analyse the three pathographies introduced in Chapter 4. When analysing the feelings verbalised and expressed in Seth, Hanna and Ruth’s stories I examine some single episodes, and the emotions they reveal, starting from the moment of diagnosis (Figure 16). The episode in question is referred to by number [S1], [S2], etc.; so the reader can easily look up and match episodes with their secondary context, which is significant when attempting to understand the mediated meaning(s).

Emotion	Seth's story	Hanna's story	Ruth's story
Shock			[R2]
Denial	[S10]		[R2]
Anger		[H8], [H13]	[R3]
Trade	[S12], [S23], [S24]		[R9]
Depression	[S21], [S22]	[H11], [H15]	[R4], [R5], [R6], [R8]
Acceptance	[S1], [S2], [S11], [S13], [S16], [S19], [S25]	[H4], [H5], [H16]	[R11], [R12], [R14]

Figure 16. Dominant emotions following the moment of diagnosis

Close analysis reveals the general lack of poetic self-expression in Seth, Hanna and Ruth's accounts. I suggest this, and a lack of description, is connected with the ethnographic style these three, along with many other writing competition participants, use to write their cancer experiences. According to Paul Ricoeur, feelings, in particular poetic feelings, imply bodily emotions, being in relation to the literal emotions of everyday life (Ricoeur 1978, 157). Such intimate self-references are not necessarily important in the context of the writing competition, however where they occur in the texts, we must pay attention to their significance.

Seth describes the moment of diagnosis as follows: *“Puoli vuotta jatkunut hajaannustila, romahdus, lähestyvän maailmanlopun tunne, epätoivoinen masennus oli saanut vahvistuksen: Kasvain! Pyörähdin melkein iloisesti tutkimussängyltä ja nostin housut jalkaani. Helpotuksen tuntein varasin seuraavan poliklinikka-ajan”*, “The half-year long ignorance, crash, the feeling of the world ending, the desperate feeling of depression received a confirmation: a growth! Quite happy I stepped down from the examination table and pulled up my pants. Feeling relived I booked the next consultation time” [S1]. To demonstrate the variation in cancer patients' writing, Seth is not in shock, but because he has already suffered pre-symptomatic conditions for a half a year, he feels relieved. He does not yet know if the growth is benign or malignant, but he has finally received an official confirmation of his inner struggle and suffering – something IS wrong with him.

Like Seth, Hanna also knows that something is not quite right with her. She is tired and she can feel something growing in her stomach. After the check-up Hanna's first idea is: *“Nyt se on sitten minussa”*, “Now it is in me!” [H4]. Hanna, however, is not relived, seemingly she is also not shocked. Her story in this sense is really more like a report. Nevertheless, she uses the word *it* to refer to cancer, a word that illustrates the culture-bound fear of naming cancer and of the concept in general. Thus, the deictic references to

cancer in episode 4 and several other episodes [see H11, H17, H18, H19], allow the suggestion that inside her body and mind Hanna feels very uncertain about her situation: partly because her individual status as a mother of a very young child, and partly because cancer's lethal image.

Unlike Seth and Hanna, for Ruth the cancer diagnosis comes as a great and foremost unexpected shock [R2]. The feeling of shock is a powerful and negative feeling, which must be expressed accordingly. Thus, for accurate self-expression Ruth has to select the proper tools. Naturally, conveying emotional experiences through language is not an easy task. The inner feelings may be named, described, or transmitted through the narrative structure (Ruth & Vilkkio 1996, 173). With culturally suppressed themes, issues that are sometimes important occur even in significant silence. The latter means that when dealing with interpretations of emotions, we may sometimes have significant context(s) mediating the feelings instead of significant words or expressions. In her story, Ruth (see below), like several other respondents, uses metaphor to describe her situation and therefore in this chapter I wish to continue discussing metaphors and what they do when placed in text.

## **The interpretation of metaphors as “works in miniature”**

Paul Ricoeur (1974, 65–110) has pointed out two main problems with the study of metaphoric expressions in text. The first problem concerns the process of interpretation, and the second the role of metaphor. As indicated above, metaphors in a text are tools of both self-expression and self-interpretation. Interpretation is generally seen as reader dependent, whereas the process of interpretation contains both textual interpretation and self-interpretation. Thus, the metaphoric expressions in text may be approached from multiple perspectives, and be understood in multiple ways. For textual studies, this means that in different texts, metaphors contain different meanings depending on the context in which they are being employed. Thus, the main problem of interpreting the use of metaphoric expressions, lies in the complexity of their character, a situation exacerbated by the desire of respondents to make their experiences understandable. Therefore, we may ask how metaphor functions and what metaphor does in written narratives that describe the moment of diagnosis.

In his writing Ricoeur asks: “Is metaphor a work in miniature?” (Ricoeur 1974, 97–98). Is metaphor the smallest possible primary textual unit within a background text? And if we

define the metaphoric expression as a primary unit, is a metaphor a narrative? In order to be defined as a primary textual unit, the metaphor must, according to Ricoeur's suggestion, adopt at least five criteria involving paradox, which I shall examine in more detail.

Firstly, to consider a metaphoric expression as a discourse it must occur as an event that includes a general meaning (event and meaning). Although metaphoric expressions are used in text in various ways, they clearly contain the idea or picture of a person being transformed as he or she moves towards a new situation. Thus, in the current context the cancer diagnosis causes for an individual the culturally accepted transformation to cancer patient. This latter contains the meaning of the transformation event.

From the folklorist's point of view, the moment of diagnosis (event) may be interpreted as a symbolic act of transformation: moving from one status to another (meaning). The metaphors used in the cancer narratives are not refined in the literary sense. To refer to their feelings people use spontaneously chosen metaphors that have a more 'fixed' meaning in culture and language:

*Sitten koitti se musta perjantai, joka pudotti minut ihan jonnekin mustaan monttuun.*

Then came the black Friday, which dropped me entirely into some kind of black hole.  
(332)

*Tultuani kotiin sairaalasta, silloin vasta tunsin kuin olisin pudonnut johonkin pimeään monttuun. Yhden illan itkin aivan ääneen, se itku tuli jostakin hyvin syvältä minusta, samalla aivan kuin olisi isketty joku leima olemukseeni: syöpäsairas, se olet nyt.*

When I came home from the hospital I felt as though I was falling into some kind of dark hole. One evening I cried out loud. This cry came from some kind of deepness inside me. At the same time some kind of stigma was set into my nature: cancer patient, that's what you are now. (155)

*Siitä alkoi varsinainen surutyö, päivisin yritin olla iloinen ja huumorikin joskus pääsi esiin. Mutta yöt olivat tuskien taivalta. Olin aivan kuin syvän kuilun reunalla. Valoa ei näkynyt mistään, ei pilkahdustakaan. Yritin tasapainotella etten putoaisi syvyyteen. Itkin itseni uneen.*

So began my sorrow. During the day I tried to be happy and even made jokes. The nights were full of misery. I felt as though I was hanging above a deep hole. There was no light to see, not a sight of it. I tried to balance and not to fall into the deepness. I cried for so long that I fell asleep. (482)

Secondly, according to Ricoeur's second paradox, the metaphor must contain contrasting traits, involving certain inner opposition (singular identification and general predication). When I was examining the narratives and deciding on themes for further analyses, I noticed the importance of nature and seasonal change for cancer patients (as already mentioned above):

*Kyllä syöpään sairastuminen, kuten muutkin vakavat sairaudet, pysähdyttää ajattelemaan tätä elämän raadollisuutta, vaikka kuinka yrittäisi näytellä toista. – Luonto tuli yhtäkkiä tärkeäksi. Maisema ympärillä avautui aivan uudella tavalla. Olin asunut neljännesvuosisadan maalla, mutta vasta sairastuttuani aloin kuunnella mm. lintujen laulua ja opetella tuntemaan eri lintulajeja.*

Falling ill with cancer, or some other serious disease, certainly makes you stop and think about the wretchedness of life, even if you try to behave as though it does not. – Nature became suddenly important for me. The surrounding landscape opened up in a new way. I have lived twenty five years in the countryside, but only after falling ill did I begin to listen to birds singing, and study different species of bird. (085)

It appears that nature in its various forms is often used as a tool for self-expression and internal identity negotiation (020, 025, 031, 064, 069, 130, 136, 153, 173, 229, 233, 236, 256, 331, 391, etc.). Accordingly, respondents make use of nature and seasonal change to express their feelings:

*Kotiin tultuani seisoin ulko-oven edessä. Asumme rivitalossa, jonka edessä on koivikko. Koivikossa oli juuri lintujen kevätkonsertti parhaimmillaan. Aurinko paistoi. Kevätuuli puhaltelee leppeästi. Totesin, että, koska voin tuon kaiken herkästi aistia ja siitä iloita, olen psyykkisesti voittanut koko syöpäjutun.*

When I arrived home I stood in front of the entrance. We lived in a row house and in front of it was a birch forest. In the birch forest birds gave their best spring concert. The sun was shining. Spring wind was blowing smoothly. I noticed that, as I was capable of sensing all of this and enjoying it, I had psychologically overcome the whole issue of cancer. (391)

Certainly, the most pregnant metaphor was a tree as a symbol both of the human being and of continuous life (016, 031, 040, 062, 098, 101, 434, 462, etc.). As I pointed out in Chapter 4, the tree metaphor already occurs in folk medical or historical cancer discourse. The image of a tree is similar to cancer, which was believed to plant roots in the body.

These roots had to be removed during the healing process (see Chapter 3). Returning to pathographies, one respondent even built up an entire story based on a birch tree with two main boughs growing in her courtyard. Her story begins:

*Kotipihallamme kasvoi kaksihaarainen koivu. jostain syystä sen toinen haara alkoi voida huonosti ja perheeni kanssa ajattelimme kaataa puun. Se oli ollut siinä koko avioliittomme ajan. Koivu kasvoi tyttären ikkunan alla ja oli muisto hänelle lapsuudesta. Kesäaamuisin sen oksilla linnut visersivät iloisina. Emme halunneet hävittää sitä. Jouduttuani sairaalaan rintasyöpä leikkauksen takia, mieheni tuli sinne minua katsomaan. Hän sanoi kaataneensa huonoimman haaran koivusta ja nyt puu muistuttaa minua. Kun nyt katselen koivua ajattelen, että meiltä molemmilta puuttuu osa itseämme, mutta saamme kuitenkin elää, sillä meitä vielä tarvitaan tuomaan iloa ja olemaan tukena läheisille.*

In our yard grew a birch tree with two boughs. For some reason the second bough began to suffer, and together with my family we thought about cutting it down. It had been there throughout our marriage. The birch grew under my daughter's window and was a reminiscence from her childhood. In summer mornings birds used to sing happily on its branches. We did not want to destroy it. While I was in hospital because of breast cancer surgery my husband came to see me. He said he had cut down the diseased bough and now the tree is reminiscent of me. When I look at the tree I think that we both miss part of ourselves, but we may live, as we are still needed to bring joy and support to our nearest and dearest.

And ends as follows:

*Kotipihamme koivu voi hyvin. Sen oksat ovat tuuhettuneet ja puu on muotoutunut kauniiksi. On kuin puu viestisi pihapiirimme iloa siitä, että se on pystynyt hyväksymään menetyksensä ja on saman vertainen muitten koivujen kanssa – ehkä vähän kauniimpikin.*

The birch tree in our courtyard is fine. Its branches have grown stronger and the tree has taken on a beautiful shape. It seems as though the tree shares its joy with our courtyard and that it has succeeded in accepting the loss, and is equal with other birches – perhaps even slightly better. (480)

Equally important is the road metaphor, symbolising the course of life, and even more significant the metaphor of a side road (the unknown path) as a representation of the illness process (025, 026, 059, 061, 111, 120, 131, 173, etc.). This refers to the ancient myth of

the journey, which according to Anne Hunsaker Hawkins is typical in many pathographies. She writes: “The use of journey theme as pathographical formulation varies from intuitive, half-conscious allusions to highly articulated mythology.” (Hawkins 1999, 80). Metaphors and metaphoric descriptions like these need careful examination in another text rather than this thesis, as they describe situations that are not covered within the current chapter. However, it is worth citing both examples – nature and the road – in order to emphasise the fact that metaphors are a very important form of self-expression for cancer patients. It is possible to argue that metaphoric expressions are not only figurative speech referring to physical sensations, but that they also, at least in the context of cancer narratives, contain representations of significant events.

Thirdly, the metaphoric expression must include some polarity between ‘I say’, and ‘I do by the act of saying’ (the propositional act and the illocutionary act). For example, the metaphor ‘fallen into deep darkness’ demonstrates how lightness turns to darkness and the sensation of being up changes to being down. The linguists Ladislav Holy and Milan Stuchlik have proposed that the way people use language is dependent on the situation in which they find themselves, and that every expression forms part of the discourse (Holy & Stuchlik 1981, 22–23). The examples given (155, 332, 482) indicate that the extent of physical feeling influences the way in which metaphor is employed. In addition, the shock caused by cancer may extend over a longer period, appearing occasionally as emotional outbursts hidden from others. In the first two of the three examples above, the diagnosis of cancer made the recipients feel ‘as if they were falling’ (155, 332), thus, by using this saying (I say), they accurately picture their feelings (I do by saying) regarding the symbolic act of transformation. In the third example, the person felt as though she was ‘hanging above a deep hole’ (482), which indicates the continuous inner struggle against the expected transformation. Thus, these examples clearly indicate the powerful nature of metaphoric expression as being dependent on situation and context, which also affects the interpretation process.

Fourthly, there must be an implied polarity between sense and reference, between what is said, and what it is said about. Here again, to trace the inner paradoxes within metaphors and to discover the fourth criterion, it is important to be aware of context and situation, and even more, of the cultural frameworks of illness discourse. In written texts, unlike oral communication, the number of thoughts that remain unfinished, and the number of implied meanings, is limited as the writer has no option for self-expression other than carefully



chosen words. The preference for metaphoric expression over culturally defined words during the verbalisation process may be explained as a human desire to be understood.

In her story, Ruth describes the moment of diagnosis as following: "*Elämäni täytti tyhjiys. Tunsin kuolevani siihen paikkaan, tai oikeastaan ajattelin, että enhän voi kuolla, koska olen täysin terve, onnellinen ja niin elinvoimainen. Kielsin koko asian*", "My life was filled by emptiness. I felt I was dying on the spot, or actually I was thinking that I cannot die, because I am fully healthy, happy and so energetic." As we are familiar with the context(s) from which this emptiness metaphor derives, it becomes easier to follow how the writer operates in this situation. First, after hearing the diagnosis her life becomes full of emptiness. This is how she feels and this also refers to her newly (although briefly) adopted condition as a cancer patient. These thoughts, however, oppose her reasoning about her health condition, so she argues, "I am fully healthy".

Willingly or unwillingly, with her selection of metaphors, she extends the meanings of her words towards what is ideologically common to language. She indicates that life with illness, as well as implementing the patient's role, is culturally understood as empty, which contrasts with the healthy life she has led until the moment of diagnosis. The healthy life is full, and not only with health, but also happiness and energy, which are not normally connected with illness. As a result of her internal, but culture-bound, argumentation, Ruth denies the whole thing.

When discussing metaphors, Mark Turner has proposed that a metaphor unites different spheres of perception and accordingly enables concepts or words to expand (Turner 1987, 17). According to Turner's suggestion, people employ metaphoric expressions to verbalise personally experienced feelings in this expanded way. As mentioned above, all human beings have their own set of physical feelings based on experience. An individual's feelings, therefore, form an inner sphere of experience. As physical experience becomes verbalised, it becomes a part of the conceptual sphere, and thus graspable by others. In fact, this assumption is one of the central ideas in linguistic discussion of the meaning of metaphoric expression in discourse. George Lakoff and Mark Johnson have suggested that metaphor guides conceptual distinction in ordinary conversation (Lakoff and Johnson 1980, 4). Consequently, the task of metaphor is to unite conceptual spheres while expanding the meaning of words.

Fifthly, the final criterion regarding the use of metaphors considers discourse as having two kinds of reference: the 'reality reference' and the 'self reference'. In this sense the expression 'falling into deep darkness' is comprehensible as an appropriate linguistic tool

for the ‘reality reference’ as well as the ‘self reference’. It accurately demonstrates the significant event of diagnosis, referring to individual feelings, the moment of transformation and the extent of feelings experienced by the patient. Nevertheless, it is interesting to observe how the selected metaphoric expression as marker of a critical transformation, becomes understandable and meaningful to the reader. In my opinion it is most important here to realise that when writing, people go through their feelings and experiences gained in the past.

Although ‘picture words’ occurring in the texts aim to recall embodied experience, their connection to reality, or the extent of ‘reality reference’, is flexible. This is connected to the verbalisation process needed to express oneself. Thus, the use of metaphoric expressions tells of the linguistic competence necessary for (written) self-expression. The metaphoric expressions in the pathographies, in a similar way to the descriptions of natural milieux, have in my opinion a strong narrative value, which allows the literary demonstration of what happened to a person diagnosed with cancer. Not all people are capable of using such linguistic tools, others might just go for words, but most importantly – as Seth, Hanna and Ruth’s stories demonstrate, lived experiences are different. Ruth’s story, also demonstrates that the metaphors used according to cultural expectation, give us access to self-reference when we see them in (un)expected situations that endanger life. Although in reality the world is not changing, people describe their sense of transformation. Polarities change, not only in the world but also within an individual: good becomes bad, full becomes empty, bright becomes dark and up becomes down. In this manner metaphoric expressions do indeed seem to appear as miniature works within the context of wider thematic narratives.

## **Metaphor as a culture-bound key to inner feelings**

As I studied the available texts, I discovered three types of metaphor used to signify the event of transformation. The cancer diagnosis may cause changes to vertical, external or inner alignment within Lakoff and Johnson’s (1980) categories of structural, ontological and orientational metaphors. Firstly, changes of vertical alignment signify movement from above, similar to the falling presented previously. In this way, cancer patients (038, 046) describe their situation as *hukkuminen* (drowning) or *uppoaminen* (sinking). The patient may also feel that *pato murtui* (“a dike broke”):

*Aavistin jonkin olevan huonosti, kun minut kutsuttiin lääkärin huoneeseen. Ruokakärryt olivat juuri käyneet, mutta siihen se ruoka jäi. "Pato murtui". Vaikka sain jotain rauhoittavaakin, tuntui kuin elämä olisi siihen loppunut. Syöpä oli silloin vielä kova sana, "Ei siitä selviä," ajateltiin.*

I sensed something was not right as I was invited to the doctor's office. They had just brought some food, but there it stayed. 'The dike broke'. Although they gave me some sedatives, I felt that my life was coming to end at that moment. Cancer was a tough word back then: 'This is not survivable,' people thought. (030)

Secondly, external changes may be projected onto the world, which stops entirely (*aika pysähtyi*) as with the first example, or onto the sky, which suddenly becomes covered with a *musta huivi* (black veil), *musta sumu* (dark smog) or *sumuverho* (smog clouds) (see also 124, 476):

*Oli se kurja päivä, kun sain sen tiedon. Lääkäri seurueineen seisoi siinä sänkyni päässä. Sanoin että se oli sitten syöpä. Niin oli, he vastasivat. Oli niin kun musta huivi olisi heitetty pääni yli.*

That was a rough day, the day I received this knowledge. The doctor stood there by my bed with his assistant. I asked if it was cancer. Yes, it was, they answered. It was as though a black veil had been thrown over my head. (023)

Thirdly, the type of metaphor represents change in the self. Accordingly, people say that the diagnosis felt like a tree trunk (*puun runko*) (462), or that a stone (*kivi*) fell on the person (*kaatui/putosi päälleni*) (046, 124). The diagnosis may also cause a feeling of cold (*kylmyys*) (046, 061, 104, 157), brokenness (*rikki*) and emptiness (*tyhjyys*) (353, 377):

*En tiedä miten kykenin ajamaan kotiin, olin ihan poikki, itketti, mutta ei kyyneltäkään tullut. Olin ihan tyhjä kuin pois heitettävä maitopurkki, pelkät kuoret jäljellä.*

I do not know how I managed to drive home. I was totally broken, I felt like crying but no tears came. I was as empty as a milk carton that ought to be thrown away, only the container was left. (046)

The role of the metaphors used as examples here is particular to the context of cancer narratives as they unite the experience, the emotions and the imagination. Paul Ricoeur has said, on the nature of metaphors, that, "there is a structural analogy between the cognitive,

the imaginative, and the emotional components of the complete metaphorical act and the metaphorical process draws its concreteness and its completeness from this structural analogy and this complementary functioning” (Ricoeur 1978, 159). Thus, changes in vertical, external, and inner alignments captured in metaphors represent the symbolic transformation process. Accordingly, what Ricoeur has called “works in miniature” accurately represents the situational changes, changes in the world, and, first and foremost, changes in the self, that make metaphor an important textual unit when ‘reading’ cancer patients’ experiences, thoughts, and, more importantly, their inner feelings.

In folklore studies, metaphoric expressions have been interpreted as the relics of mythical reasoning (Siikala 1992, 155–183), or, in contrast, as representations of organised human reasoning set within a particular context. (Apo 1995, 26–29; 2001, 66–68; Timonen 2004, 307–328; Tarkka 2005, 76–79) Therefore metaphors transmit ancient human experience, while in certain situations they appear as context dependent representations. For example, sorrow as an emotion may be described as a central feeling in Kalevala-metre lyric songs. According to Finnish folklorist Senni Timonen, this emotion is described as something inside the singer’s body: in the head, in the heart, in the torso or under the feet. Folk singers picture their sorrow as feeling like ice or burning like fire. Sorrow may also appear as a being who changes the self (Timonen 2004, 326–328). It seems that the images of transformation used in cancer narratives represent mythical thought, acknowledged as a well established, pre-existing, part of culture. I suggest that the poetic freedom present within metaphor is used when respondents construct their particular “work in miniature” and make it a part of their thematic writing. Metaphor contains the freedom to choose a suitable word order, as well as the requisite amount of emotion in order to mediate the situation in which cancer sufferers find themselves.

As the relics of mythical reasoning, metaphors constantly reappear in new contexts and situations. To understand this statement, it is necessary to return to Paul Friedrich’s assumption about the culturally complex nature of metaphor posed at the beginning of this chapter. By its origin, metaphor is culture bound and rich in mythical images. Within the text, this image becomes interpreted and verbalised either consciously or subconsciously according to the situation and context. Metaphor may be defined as a heterogeneous tool containing linguistic code. This code mediates our cultural, social, and poetic understanding of the world, for example making the metaphor “the sinking ship” (Lakoff and Johnson 1980) into a true image of serious trouble.

From my point of view, what metaphor does regarding the moment of diagnosis in cancer patients' writing is crucial. Following on from Senni Timonen (Timonen 2004, 309), I want to point out that metaphor works as a culturally bound key to the world of emotions. In the form of a work in miniature work metaphor allows people to describe their feelings about significant experiences. As representations of personally experienced shock and transformation, metaphors appear as coherent, poetic, utterances within the cancer narratives. Thus, they give an opportunity for a reader to understand, picture and feel the lived emotions of cancer sufferers.

## Conclusions

The moment of cancer diagnosis may be interpreted as the most crucial in the cancer experience. A moment which, for many cancer patients, causes inner chaos and loss of self. The metaphor appears to be an excellent linguistic tool, extending the empirical and conceptual spheres and making real events and personal emotions comprehensible in a variety of ways. I concentrated on the metaphors used in Finnish cancer patients' written narratives because these texts create a suitable context within which to understand that metaphors are, in primary terms, used for self-expression and self-interpretation.

Approaching metaphors from multiple perspectives demonstrates the significance of metaphors as works in miniature when they refer to an individual's emotions at the time of diagnosis within the context under study. The use, meaning and function of metaphors within the discourse on a particular culturally stigmatised illness, namely cancer, demonstrates how experience becomes verbalised and expressed as a culture-bound key with which to comprehend, and make comprehensible, individual emotions.

When using metaphors, cancer patients are able to demonstrate their changed situation: their transformation into cancer patients. This particular event, represented in metaphor, contains respondents' feelings about the cancer diagnosis as well as their cultural understanding of being a cancer patient. Individuals suddenly face the world from a different perspective. The outside world is no longer the same, and, which is more important, as a result of these changes people with cancer do not feel themselves to be the same people they were before their diagnosis. They have *become* cancer patients.

## **7 Patients' Feelings About Deficiencies in the Biomedical Healing Drama**

Illness has never been exclusively an individual problem. Individuals, and the society in which they live, understand illness as a social crisis that must be solved quickly using all available knowledge (Honko 1993, 523). Therefore, in every society a fixed social setting exists for human behaviour when a person falls ill. Within this social setting the moment of diagnosis becomes a marker for the beginning of a pathological drama. In an ideal case the pathological drama or illness process lasts until the illness is cured and the person is declared healthy again. Unfortunately, having cancer does not fit in the category of normal pathological drama.

New diagnostic techniques, such as X-ray screening, CAT scans (Computerised Axial Tomography), ultrasound and MRI scans (Magnetic Resonance Imaging) have brought advantages in the early detection of cancer. In some cases diagnosis saves lives, however the problem is that these diagnostic advantages have outstripped the cures. According to Roy Porter, despite numerous victories in the biomedical field, no 'magic bullet' has ever been found to cure cancer: surgery, radiotherapy and chemotherapy offer relief far more often than a cure (Porter 1999, 576–578; see also van Helvoort 2001, 33–60). Although cancer survival rates have increased rapidly over past decades (see Finnish Cancer Registry, Newest survival rates) there is still too little information about how cancer patients themselves feel during the biomedical healing process and how they actually 'survive' their illness. I emphasise that under such conditions, where the final outcome is rather uncertain, it is very important to offer cancer patients all kinds of support to improve their condition. This suggestion is based on the cancer patients' narratives that indicate the situation is somewhat problematic in modern healthcare centres. The main criticism considers the occasions when patients are handled as medical cases or diseased bodies, and are left without individual support from the doctors' side. Based on my material I suggest that the more human approach is an important goal that doctors should be working towards for a more satisfactory outcome.

Adopting the patient's role means that people are forced to go through socially approved 'rites of passage' in order to become well again. Biomedical treatments given in hospital are attempts to stop cancer cells from destroying the human body. According to cancer patients' descriptions, the treatments may be so vicious that they change a healthy

person into one who is suffering. This means that patients lose control over their bodies. Regarding chronically ill and terminally ill people, Cheryl Mattingly has suggested that “when illness is protracted, when there is no hope of being ‘normal’, a person’s very sense of *self* is lived in a special way through the body. Personal identity becomes intimately tied to the pain, uncertainty, and stigma that come with an afflicted body.” (Mattingly 2004, 73) Cancer patients, and those who are made temporarily ill by medication, find themselves in a rather similar situation. Even if the personal condition turns for the better and the connection with a person’s own body grows stronger, it is difficult to get rid of the images of the self as some kind of “diseased being” (Soivio 2003, 110). Therefore, the individual experiences gained through the officially approved healthcare institutions are described as significant and challenging when we consider the individual illness process in terms of becoming well. In their writing, cancer patients express the view that the biomedical treatments offered by society are not enough to become well. People crave holistic attention because they perceive that this would unite treatment of the body with an individual’s emotional needs.

The individual challenges people face as patients in the cancer clinics describe the changes in the individuals’ position while in the role of cancer patient. Even if people get used to hospital rules and routines, the time spent in hospital represents a period of losing control over one’s life. Furthermore, cancer patients’ narratives say that when treated under such uncertain conditions it is difficult to trust physicians, particularly because communication between physician and patient is often built on silence. Based on the cancer patients’ narratives, I suggest that this unwelcomed silence from the physician’s side should be replaced by a healing drama that contains narration and integrates an individual’s experience of life. From the ethnomedical perspective such change would also promote better results in the field of biomedicine.

## **Towards modern healthcare institutions**

In Finland the change to centralised healthcare institutions began in the 1950s. Before this change patients in need of medical help could turn to community doctors, who typically took care of whole families from new-born babies to grandmothers. Community doctors, who worked for several decades in the same place, were aware of their patients’ living conditions as well as their qualities as an individual. Although patient numbers were high

and doctors were expected to work with little rest, in writing collected from physicians, biographies, etc., work as a community doctor has been described as rewarding (see for example Pesonen 1990, Kantele 2006, Pasternack et al. 2006). Physicians' reminiscences point out that respect for the community doctor was high. Because of their ability to help, doctors were often regarded as superior people and thus their opinion was significant to patients. The traditional way to think about physicians as superior beings is often described in cancer patients' writing:

*Niihin aikoihin [1950-luvulla] suhtautuminen lääkäreihinkin, ja heidän suhtautumisensa potilaisiin oli kovin eri laista kuin nykyisin. Lääkäreitä kunnioitettiin tavattomasti, jopa pelättiin. Ei heidän tarvinnut antaa tietoja potilaalle. Viitataan isäni tapaukseen [1950-luvun alussa]. Hänhän sai tietää vasta leikkauksen jälkeen syövästään. On myös otettava huomioon, että niinä aikoina "otettiin vastaan, mitä annettiin", eli: oli opittu mukautumaan vastoin käymisiin.*

In those times [the 1950s] attitudes towards doctors, and their attitudes towards patients, were very different from today. Doctors were respected, even feared. They did not have to share their information with patients. I refer to my father's case [the beginning of the 1950s]. He received the knowledge about his cancer after the surgery was done. One has to have in mind that at that time people 'accepted what was given', meaning: people were used to all kind of challenges. (205)

This kind of inequality meant also that many doctors handled their patients as totally ignorant. The book *Lääkärintyön muistoja. Läkärinmen* (Reminiscences of the Physician's Work, 2006) containing the reminiscences of Finnish physicians, includes an interesting description of medical training in the 1950s. The writer recalls her professor's words regarding people who come to visit the doctor. According to the professor, patients may be divided into two groups: a) the uneducated, who do understand nothing about these things; and b) the educated, who understand equally little (Paljakka 2006, 47). Instructions given in the book suggest that patients should obey doctors' decisions without asking any further questions, which means giving up individual control.

Comparisons between the doctors' reminiscences and patients' writing from the time before centralised healthcare institutions were established, demonstrate that doctors alone bore responsibility for the treatments given and their final outcomes. Although the available resources and the work conditions were poor, people who came with their health concerns to doctors were in confident hands. In contrast to today, the trust shown in a



doctor's skill and 'superior' position was acceptable for most of the patients because the doctor was (in most cases) familiar with his or her patients as individuals.

As the new centralised healthcare system gained its dominant position, the situation changed radically. The Finnish community doctor Leo Saloranta has argued that the change towards the modern healthcare system caused two major errors. The first was that doctors were made state employees, instead of being independent suppliers. The second was the change of the community doctor system to centralised healthcare, meaning that, in theory, the responsibility for the patient's condition and cure belongs to the chief physician at each healthcare centre, but in reality no one cares (Saloranta 2006, 94). The implementation of centralised healthcare meant that the treatment opportunities were more advanced, as the doctors were supplied with better equipment and facilities; however, the relationship between doctors and patients became distant, and thus, patients were no longer sure if their health was in the hands of people who truly cared. Consequently, in the cancer narratives the current situation in the Finnish healthcare system is described as a period in which new technologies and complex treatments dominate over the human being, and the integration of patients as individuals has lost its significance:

*Juuri lääkäreiden taholta saatava rohkaisu on ollut kiven takana. Tai oikeammin sanottuna sitä ei ole ollut ollenkaan. Ja kuinka kipeästi sitä tarvitaan psyyken "jälleenrakennusvaiheessa". Olen käsittänyt että vältetään väärän toivon antamista potilaalle. Jo käsitteenä "väärä toivo" on mieletön. Sitä paitsi toivottomuudessa eläminen vie lopullisesti ne voimavarat joita potilas tarvitsee selviytyäkseen joka päiväisestä elämästä. On ollut vaikeata kohdata se asenteellisuus, jolla liian helposti leimataan koko potilaskunta yhteneväiseksi ryhmäksi, ihmisiksi jotka sairastuttuaan vakavasti kokevat sairautensa ja sen tuomat ongelmat kaikki samalla tavalla. Jokaisellahan meistä on oma historiamme ja sairaudesta huolimatta olemme yksilöitä.*

The encouragement coming from doctors has been lost. Or to be correct it is non-existent. And how much people crave for it in order to 'build up the self'. I have understood that in this way doctors try not to give any false hope to patients. Already as a concept false hope is crazy. Living in hopelessness takes the last energy a patient needs to survive daily life. It has been difficult to accept this viewpoint, which far too easily labels all patients as part of the same group, as people who experience serious illness and all its complications in the same way. Every one of us has his or her own history, and despite illness we are individuals. (195)

Physicians working in hospital concentrate on curing the illness, which in the first place can mean removing the dysfunctional part(s) from a patient's body using surgical routines. Chemical therapies are implemented to stop the spread of mutant cells. Thus, in cancer clinics, cancer is handled as a non-human and independent phenomenon. In this sense, for physicians the 'medical body' in their explanatory model is no longer the diseased patient, but the mutant cells or tissue (Helman 2000, 27). According to Lauri Honko, the conventional medical paradigm has gone through a two-step alienation of the human being. Firstly, the biological approach requires the excision of illness, usually necessitating the illness to be treated without the inclusion of the person in the treatment process. Secondly, where there is a need to include the person, the patient may be treated as a disease carrier, a non-human separated from their social context (Honko 1983, 36). Consequently, the treatments offered mean that patients, with their individual feelings, needs and lived experiences, are left without attention.

## **Passive and patient**

Because of cancer's biologically unique nature, the period of being a cancer patient may be delineated only by the time of surgery spent in hospital. Then again, for others the pathological drama signifies an extended period filled with physical and psychological suffering taking place partly at home and partly in different healthcare institutions. Consequently, the period of the pathological drama, and of being officially recognised as a cancer patient, are for many reasons puzzling concepts. The official declaration of a cure for a patient's cancer may take up to five and in some cases even ten years. In order to distinguish between the pathological drama and the healing drama discussed in the following pages, I emphasise the change in culture-bound thinking about the individual's responsibilities as they relate to an individual's health as the illness attacks.

In everyday life people are encouraged to take care of their bodies. As I demonstrated in Chapter 5, people are rather well aware of all kinds of preventative suggestions made by health authorities, although following these is for many reasons complicated (Eriksson-Backa 2003, 175–181). When illness attacks, the cultural agreement of an individual being responsible for his or her own health breaks down and poor health becomes the problem of society. To their surprise, people notice that they are no longer in charge of their bodies and what happens to them. Being involved in a pathological drama as patient means that people

working in healthcare institutions gain control over a person's body and start to make significant decisions concerning his or her life. This kind of situation, in which individual decision making has only a secondary (not to say irrelevant) role, makes people feel uncertain and confused, particularly as the new situation is one of contradiction of the generally understood cultural agreement. In this way patients' feelings about their time spent in hospital is an interesting subject for observation.

In his article on patients' competence *Sairaan asiantuntijuus* (The Competence of the Sick Person, 2003), Finnish sociologist Ilka Kangas concluded that, compared to diabetes, allergy and depression, cancer patients are less active when it comes to their treatments, and indeed the whole pathological drama. She suggests that cancer patients are less interested in their treatments and they often leave the decision making to doctors and medical staff (Kangas 2003, 86–87). To reach his conclusions Kangas used 21 cancer narratives from the same text corpus that is under observation in the current work. According to my expertise, Kangas' statement regarding the passiveness of cancer patients is misleading and needs to be corrected for this context.

In fact, in their writing cancer patients negotiate and propose many aspects of their treatment that they feel should have been taken into consideration or done differently in the hospital, as well as throughout their pathological dramas. Bringing out faults and mistakes that have occurred in hospital is part of the responsiveness characteristic to ethnographical writing. Respondents share their wish to be heard and noticed by medical staff. It appears that in the hospital, and during the healing drama, cancer patients are actually left without any personal opinion or the possibility to give feedback actively. Indeed, the biomedical treatments given to cancer patients are compared to other common long-term illnesses that are considered beyond everyday understanding. This however does not mean that people stop thinking about what is the best way for them to become well. If they did, the outcome would not be beneficial to anyone. Therefore, regarding cancer patients' actives, or to be precise, their inner desire to be involved in the healing drama, in reality every individual is interested in his or her health condition (see also Hawkins 1999, 129–130). Awareness of personal health is also supported by society, although unfortunately cancer patients treated in cancer clinics are in general given no choice other than to be passive and patient.

## Patients' experiences in healthcare institutions

The time spent in the hospital may be experienced and interpreted in multiple ways like all other events that gain significance in human life. In cancer narratives patients' feelings generally have a retrospective character, which means that the primary sensations and significant events are evaluated as being past events. I emphasise that respondents' attempts to discuss the time spent in hospital and their role as cancer patients is foremost influenced by the question posed by the organisers of the writing competition: *Explain how people at the hospital acted towards you as a person and a patient? Did you feel safe and did you get enough support and information?* Being encouraged by this question people eagerly shared their concerns and feelings on this topic.

Patients' past experiences influence the frank descriptions given in the written narratives. In some, hospital is described as a safe place where everybody is "wounded" in some way and people at least hypothetically do not judge others according to social and cultural expectations (057, 142, 391). Other people in the same situation suffer from the lack of sympathy, support, and understanding (048, 120, 158, 164, 203, 222, 223, 257, 298, 330, etc.). The reasons for this lie in cancer's culture-bound image and the physical suffering it causes:

*Ehkä syöpä on sen kokeneelle niin pelottava asia, että mieli on koko ajan äärimmäisen herkkätuntoinen kaikelle kohtelulle. Potilaana on lisäksi niin hoitohenkilökunnan armoilla, että oma persoona ja sen rationaalinen minä tahtoo helposti olla kadoksissa.*

Perhaps cancer is so terrifying a thing that it makes you extremely sensitive to everything. As a patient, you are so dependent on hospital personal that your own personality and its rational self get easily lost. (331)

According to cancer patients' descriptions, entering hospital could be described as experiencing the self placed in an unnatural environment full of challenges. The contradiction between the everyday or 'natural' surroundings of human life and the situation within the clinic may be described as denying access to natural surroundings. In everyday life people are able to enjoy the weather, trees, seasonal change, etc., whereas in hospital, where the pathological drama is handled, patients may observe nature and life outside only through the windows. This feeling is similar even if patients visit hospital for a short period or even for a few hours. The difference between 'normal life' and the abnormal situation patients find themselves in may come from simple restrictions, for

example on driving a car, often seen as a symbol of freedom (289). Indeed, the hospital walls restrict patients' freedom and in this way, and not only symbolically, patients are kept apart from the 'normal' world and 'normal' people.

Entering hospital also means that people must go through certain rituals before they are accepted as patients. In Finland people are forced to give up their personal clothes and other belongings, and must put on hospital garments after entering the hospital doors. In this context, removing personal clothes signifies a symbolic act that takes identity away from individuals:

*Kaunis, aurinkoinen helmikuun päivä. Pakkasta 15 astetta. Puut kauniin huurteisia ja oksissa kimaltelivat lumihuutaleet. Kaunista ja valoisaa. Oma mieleni ei ollut valoisa. Katselin maailmaa sairaalan viidennen kerroksen ikkunasta. Tulin kylpyosaston kautta, kuten sairaalaan yleensä tullaan. Siellä ihmiseltä riisutaan henkilökohtainen minuus. Olen potilas se ja se.*

February, a beautiful sunny day. 15 degrees below. Trees covered with beautiful frost and in the branches snowflakes shine. Beautiful and bright. My own mind was not bright. I looked at the world through a window on the fifth floor of the hospital. I entered through the bath department, as it is usually done. There they 'unveil' the personal ego. I am a patient this and that. (158)

*Tuo lääkäri ei katsonut tarpeelliseksi minulle kertoa asiasta sen enempää – pyysi odottamaan käytävällä. Jonkun ajan kuluttua hoitaja toi minulle muovipussin, jonne täytyi laittaa omat vaatteet. Ihmisarvoni tuntui alentuvan olemattomiin.*

That doctor did not think it was necessary to tell me more – he asked me to wait in the lobby. After some time a nurse brought me a plastic bag where I had to put my clothes. My human value seemed to disappear entirely. (360)

Hospital represents a place where people get help and support from professionals as well as understanding from others in similar circumstances (057, 142, 158). In hospital people make friends with other patients and learn to support and help each other, build up a small society or a temporary community of suffering. Therefore in some cancer narratives the period spent in hospital reminds people of good team spirit: laughing, crying and making the first steps together in order to become well again:

*Leikkauksen jälkeisenä päivänä alkoi kova kuntoutus. Olimme päättäneet kohtalotoverini kanssa, että tästä selvitään. Heti kun sai lähteä liikkeelle, lähdimme kävelylle sairaalan*

*käytävälle. Hyvin sitä jaksoi olla jalkeilla. Mietin, ettei tähän varmaan heti kuole, kun en tunne itseäni yhtään sairaaksi.*

The day after the surgery our fitness training began. With my friend in destiny I had decided that we shall survive. Immediately we could move we made a walk in the hospital corridors. We had enough energy to stand on our feet. I thought that I am not going to die of it immediately, as I did not feel myself sick at all. (142)

The social contacts or relationships made in hospital are important, and according to cancer narratives last for the rest of the patients' lives. Fellow patients may even occur in dreams:

*R. – potilastoveri, häneen olin tutustunut sairaalassa soitti kerran ja kertoi nähneensä merkittävän unen. Olimme olleet isossa porukassa siis paljon ihmisiä, nähtävästi meitä syöpäsairaita, niin hän asian selitti. Olimme saaneet lähtiessä muistoksi pienet kirjat, hänelle oli annettu kirja, jossa oli teksti “Viimeinen portti”! Minä sain kirjan, jossa luki “Jatkoaika”. Tästä tapauksesta on jo yli kolme vuotta. R:n sairaus uusi aivan yllättäen – hoidoista huolimatta sairaus voitti ja hän menehtyi noin vuoden sairastettuaan! R:n sairaus kosketi minua kovasti, se oli raskas vuosi nähdä ystävän kärsivän enkä voi auttaa! Tulee usein mieleen ne keskustelut joita kävimme hänen kanssaan, hän sanoi unen käyvän todeksi, koska hän tunsu voimansa vähenevän ja lähestyvänsä “viimeistä porttia!” Minulle hän sanoi “käytä tämä jatkoaika mahdollisemman täyspainoisesti, hoida itseäsi, anna aikaa itsellesi!” R:lle portti aukesi rauhallisesti hänen nukkuessaan!? Tällaista lähtöä toivoisin minäkin. Sitten kun minun “jatkoaika” päättyy.*

R – the fellow patient I had came to know in the hospital called me to say she had had a significant dream. We were in a big group, apparently all cancer patients, as she explained it. We had received little books as souvenirs, whereas she had a book containing a text: “the final gate!” I got a book in which was written “continuation time”. This happened three years ago. R's illness returned suddenly – despite treatments the illness won and she died in a year! R's dream moved me a lot, this was a hard year to see a friend suffering without any chance of helping! I often remember the discussions we had, she said her dream will come true, because she was losing strength and approaching the “final gate!” To me she said “use this continuation time in a balanced way, give time to yourself!” R's gate opened as she was asleep! This kind of departure I wish for myself as well, when my “continuation time” is over. (240)

On the other hand, patient relationships in hospital can be also an intensive period of communicating and sharing, without the expectation of seeing these people in the future. Such a situation may be very fruitful for making anonymous, but very intense, connections.

When it comes to the patient-doctor relationship, one has to bear in mind that communication in hospital happens according to hospital rules, which makes individual values and personal qualities less significant (Goffman 1961, 22). To feel good in hospital people must learn to act and behave according to hospital rules. Even more, they also have to learn hospital language in order to know what is going on. Despite the potential support and help it is challenging to accept the patient's role in hospital. According to cancer narratives, being in hospital is like being in unknown territory. Instead of feeling safe, people feel themselves to be like a lost tourist "without a phrase book". The metaphoric expression 'feeling like a tourist' may be interpreted as an uncertainty experienced in connection with entering the new social setting:

*Olo on kuin olisi oppinut kokonaan uuden kielen. Karsinomat, biopsiat, metastaasit, ablaatiot, endokrinologiset, ym. kuuluvat lääkäreiden mielellään käyttämiin sanoihin. Aluksi tunsin itseni sairaalassa turistiksi, joka on vieraassa maassa eksyksissä ilman sanakirjaa!*

I feel like I have learned a whole new language. Carcinomas, biopsies, metastasis, ablations, endocrinologist, etc., belong to the vocabulary often used by doctors. At the beginning I felt myself like a tourist in the hospital, lost in a foreign country without a phrase book! (257)

*Minäkin opin hienoja sairaala termejä käyttämään ja tiesinkin veren kuvat ja muut muutokset, mutta tavalliselle ihmiselle ne ovat vaikean selkosia, pitäisi kysyä miten te jaksatte, miten voisin auttaa.*

I learned fancy hospital terms and I knew everything about blood pictures and other changes, but for ordinary people these are difficult to understand; instead people should be asked how they are doing, and how they could be helped. (011)

Initially, patients feel particularly insecure because they are not familiar with the hospital's rules of behaviour and do not understand the language in use. The idea of being like a tourist shows patients' ambiguity towards biomedical treatments, physicians' competence and the outcome of the treatments given. Furthermore, people are also often confused by the occurrence of cancer. Thus, as one respondent explains, cancer treatments

feel like “*taistelua näkymättömällä näkymätöntä vastaan*”, “a fight with invisible [methods] against the invisible” (352). This thought is connected to the fact that in the biomedical sense cancer has no shape or form, at least in its early stages. As people cannot see or feel cancer in their bodies, the treatments seem unnecessary and even absurd. The latter feeling is highlighted by the fact that people feel sick *after* the treatments are given (see for example 549, 555).

As time passes, people become accustomed to medical terminology and the daily routines of the hospital. As this happens, the rules of the clinic become clearer, and the hospital milieu begins to offer a certain safety, support, and even protection from the everyday expectations which, particularly those who do not suffer from cancer, could have towards those who do. Being in hospital offers protection from daily challenges, because as one respondent points out, those without cancer often lack the energy and will to understand the sufferer’s situation (196). Being directed by hospital routines, a patient’s sense of reality becomes separated from his or her everyday life. Daily procedures direct the flow of time, where visits from relatives and friends represent the highlights of patients’ days:

*Kohokohtia sairaalassa ollessa olivat ne hetket, kun joku kaveri tai sukulaiset tulivat katsomaan. Tuntui kummalliselta kuulla kaverin suusta selityksenä, kun ei ole käynyt katsomassa, että on kiire. Minulle sellainen asia oli niin kaukainen, minulla ei ollut kiirettä enää minnekään. Minulla ei ollut muuta kuin aikaa.*

The highlights of the time I spent in hospital were when some friend or relatives came to visit me. It felt odd to hear explanations like not having time to visit me from a friend, when they were in a hurry. For me this kind of thing felt so far away, I had no hurry anymore anywhere. I had nothing but time. (139)

In their writing several respondents point out that the loss of self in hospital is unbearable. Even if people get used to hospital rules and routines it does not mean that they would feel entirely happy in this situation. The protective walls of the social context of familiar everyday life are taken down, while patients are handled as medical bodies and thus often feel *riisuttu* (unveiled) as individuals. Far too often being a patient also means being *julkinen asiakirja* (an open record), whose concerns and treatment complications may be shared in public:



*Intimiteetin menettäminen sairaalassa on järkyttävää. Samalla kun vaihtaa sairaalan vaatteet ylleen tulee julkiseksi asiakirjaksi. Potilaan sairautta käsitellään vuoteen vierellä muiden potilaiden kuulleen. Vuoteenvierusraportoinnista voi kyllä kieltäytyä. Kuitenkin käytännössä potilas näkee lääkäriä vain kierroksella. Milloin potilas kysyy lääkäriltä sairaudestaan, jos ei kierroksen aikana? Muiden potilaiden sairaskertomukset masentavat yhtä paljon kuin oma läpikäyminen. Miksi sairastamisen pitää olla julkista sairaalassa?*

Loosing privacy is terrible in hospital. At the same time you put on hospital clothes you become an open record. A patient's illness is handled near his or her bed while other patients are listening. You can of course disagree with such near bed reports, however, in reality patients see doctors only during the rounds. When should the patient ask about his or her illness if not at the time of the round? The illness stories of other patients are as depressing as my own suffering. Why must being ill be public in hospital? (120)

*Lääkäreiden kierrot olivat välillä hyvin ärsyttäviä, sillä usein hoitohenkilökuntaa oli sängyn ympärillä hyvinkin monta. Siinä tunsin itsensä apinaksi, jota tullaan tuijottamaan. Kerrankin olin ollut suihkussa ja istuin alasti vessan pöntöllä, kun lääkärin kierto oli. Vessan ovi vain avattiin ja siinä olin alasti kaikkien tuijotettavana. En jaksanut edes suuttua. Alistuin kaikkeen./---/ Potilaana sain nähdä, miten todella ihmisarvoa alentavalla tavalla potilaisiin suhtauduttiin. Ihminen ei voi enää kovin sairaana puolustaa itseään, joten hänet lähes esineellistetään ja kohdellaan kuin esinettä, jolla ei ole tunteita.*

Doctors' visits were sometimes really annoying as there were lots of people gathered around my bed. I felt myself to be an ape at whom people come to stare. Once I was taking a shower and sat naked on the toilet seat as the doctors came. The door was opened just like that and there I was naked ready for everybody to stare. I even did not have the strength to become mad. I just gave up. /---/ When I was a patient I could see, how patients were put down as humans in a humiliating way. When feeling really sick people cannot protect themselves, so they are almost turned into items without feeling. (223)

Cancer narratives point out that clinics offer little space for patients to be emotional or deal with personal needs. People going through physical alteration face psychological challenges and would therefore definitely need some privacy to gather their thoughts and rebuild themselves. However, the space for private needs is not available and this gives people a feeling that they are handled as non-humans or items. Potential support from outside is reduced to a minimum because it is not possible to discuss your problems

without other patients listening. The same is true of sharing the words of support and love, not to mention sharing physical contact. The lack of privacy causes inconvenience and feelings of shame:

*Sairaalan osastolla olivat paikat täynnä. Usein käytäväpaikatkin olivat käytössä. Opin kaipaamaan yksityisyyttä. Opin sitä myös arvostamaan. Sen toteuttaminen ei ole helppoa, aina ei edes mahdollista. Kierolla osastolla käsitteellään asiiasi kaikkien kuullen, haluaisit sitä tai et. Lääkärin ja hoitajien haastattelut tapahtuivat myös potilashuoneissa, joissa on toinen potilas, ehkä useampiakin. Kuulen asioita, joita en välttämättä haluaisi kuulla, joiden tietäminen ei ole minulle tarpeen. Toinen potilas kuulee minua koskevia. Joskus mietin, olinko itse ollut kyllin hienotunteinen ja lähtenyt pois potilashuoneesta hoitotoverini haastattelun ajaksi. Aina sellainen ei ole edes mahdollista.*

All the places in the hospital were full. Even the corridors were in use. I learned to miss my privacy. I learned also to appreciate it. To make it true is not always easy, not even possible. As the physicians make their rounds, your case will be handled in front of others, either you want it or not. The interviews between doctors and patients also take place in the hospital room where other patients are, sometimes even more people. I hear things that I do not necessarily want to know, that I do not have to know. Other patients hear about me. I have been thinking if I have been tactful enough to leave the room while the other is questioned, sometimes this is not even possible. (330)

In a similar manner, clinical procedures also cause inconvenience and embarrassment. People have to accept their altered bodily condition: weakness, pain, lack of appetite, nausea and numerous other complications or side effects that are directly connected with biomedical treatments. The reason is the same – the individual with her or his inner feelings and needs is being excluded from the healing drama (164, 201, 203, 278, 360, 378, 390, 397, etc.). This means that cancer treatments given in hospitals leave profound imprints on the human body and on the self.

## **Physical change and its importance to the patient while in hospital**

The sociologist Arthur W. Frank, with the embodied human experience in mind, has suggested that cancer clinics may be defined as institutions or places in which the body gains new significance, giving new meanings to the self (Frank 1991, 49). The physical

experience, which is very significant to cancer patients' everyday lives, takes on a different value in written narratives – it becomes a fixed interpretation of individual feelings that must gain certain structure, to be understood by others. Because of its ethnographic nature, cancer patients' writing highlights above all the cultural dimension of the discourse. In this discourse the embodied experiences gained in the hospital are represented only as a metadimension belonging to the cancer experience. By which I mean that the 'cuts' to the body and other similar memories are gained in the hospital, but that their importance grows as people are confronted with the normal setting of everyday life, including cultural expectations towards one's body.

For example, losing hair is a terrible thing from the cultural point of view as shaved heads traditionally symbolise radically marginalised positions in society (Bromberger 2007, 394). Cancer patients are culturally taken to be in the marginal position anyway, and if they lose their hair, the stigma becomes visibly detectable. From the biological and medical point of view, hair loss is not an issue, but from the cultural and personal perspective it may be very important. Therefore it should be taken into consideration when dealing with such issues:

*Kun tästä tuken lähdestä puhuin yhdelle hoitajalle hän väheksyi huoltani sanoen, että eihän kalju ole miehelle mikään paha asia. Minulle se oli erittäin arka asia kaiken muun lisäksi. Hoitajan mielestä syöpäpotilas saa näyttää miltä vaan. Pääasia on, että häntä hoidetaan.*

When I mentioned losing hair to one nurse, she told me that being bald is not so bad for a man. For me it was a really bad thing in addition to everything else. Nurses think that a cancer patient may look like whatever. The main thing is the treatment. (278)

*Solumyrkyt aiheuttivat myös sen, että minulta lähti hiukset. Oli kamala tunne aamulla, kun katsoi tyynyä, joka oli peittyneenä irronneisiin hiuksiin. Häpesin valtavasti kaljua päätäni. Keväällä hävetti kulkea pipo päässä, kun muut olivat avopäin.*

Because of cytostatic treatments I also lost my hair. It was a terrible feeling in the morning when I looked at my pillow covered with hair. I was ashamed by my bald head. In the spring I was ashamed to walk with a cap on as others were without. (139)

Patients' memories about their bodies, described in my materials, have to be seen as to some extent different from their everyday experiences. The body memories, such as loss of a breast, or even both, or loss of reproductive organs or hair, derive from the hospital

setting but are not necessarily first in the line of patients' reminiscences gained in healthcare centres. The written texts indicate that to cope with the illness and changed body image, the 'sense experiences' gained during the healing drama in the cancer clinics are essential:

*Tuli aika katsoa peiliin. En huutanut, pyörtynyt. Näin teipillä peitetyn pitkän haavan. Rintaa ei ollut. Asian hyväksymisessä vammaisuuteni auttoi. Minulla ei ole mannekiinin vartaloa. Kotiinlähtöä edeltävänä yönä valvoin. Sairaalassa ollessa on "turvassa". Sieltä löytyy aina joku, jolle voi puhua sairaudestaan ja pahasta mielestään. Ystävillekin kyllä, mutta ei aina. Sairaalassa on myös "puolueettomalla" maaperällä, kaukana ympyröistä, jossa tämä asia on hyväksyttävä ja opittava sen kanssa elämään.*

The time came to look at myself in the mirror. I did not scream, did not faint. I saw a long wound covered with tape. No breast. The fact that I was disabled [childhood tuberculosis] help me to cope. I have not the body of a model. The night before going home I could not sleep. In the hospital you are 'in safety'. There you always find someone to whom you may talk about your illness and upset mind. With friends as well, but not always. In the hospital you are also on neutral ground, far away from the surroundings in which this thing must be accepted and coped with in order to live with it. (158)

As I have demonstrated above, many respondents wish that doctors and other medical personnel would notice and approach them as individuals. This however seems impossible, as the situation is one in which contact between patient and doctor is reduced to a minimum. The changed body condition and its cultural and personal significance, as well as patients' other feelings about the self, are often interpreted as insignificant within the medical paradigm as long as the patient stays alive. Modern doctors working in centralised hospitals are seldom familiar with their patients, which means that in practice doctors only deal with the biomedical challenge. As part of their duty of care, doctors aim to repair, remove or replace dysfunctions at the biochemical, cellular and even molecular levels. In my opinion justifiably, patients find it objectionable to be reduced to a set of biological functions in this way. Cancer patients prefer to be approached as a whole person including body, soul and spirit (330). Considering the cancer patients' culturally vulnerable position and cancer's complicated nature, I wish to suggest that all cancer patients need their doctor's full attention, including empathy and psychological support.

## Silent doctors

In his article about culture and illness Lauri Honko has pointed out that when illness is interpreted as a message used by patients to express their life situation, the message stays unread as the doctors concentrate only on removing the illness (Honko 1994, 17). As pointed out in Chapter 5, which deals with popular explanations for cancer, cancer patients often argue that falling ill with cancer is connected with their individual life course. Unfortunately, patients' individual explanatory models are almost never considered by medical practitioners; rather, Finnish doctors prefer to stay silent. One respondent even compares the relationship between the patient and doctor as equal to that between God and his earthly servants, in which the latter may pray, but the answer never comes: *Potilan ja lääkärin suhde on kuin rukoilijan ja jumalan* (306).

Subjective and culture-bound ideas about cancer's origin differ from the rational and evidence-based explanations used by medical professionals. For cancer patients, however, cancer is not simply the territorial expansion of a mutant clone, it means much more. Cancer could be interpreted as an individual tragedy causing physical, psychological and social suffering. In this situation, patients desire a sufficient patient-doctor relationship in order to find a mutually satisfying explanation for a particular illness episode, and in order to help in their aim for holistic recovery. Unfortunately, the analysed cancer narratives reveal doctors' unwillingness to discuss the individual course of the illness with their patients: the reasons for cancer's occurrence, the meaning of the treatments given and the achievable outcome. Instead, these narratives show doctors as distant and overconfident professionals persistently short of time.

I have previously discussed the meaningful silence that surrounds cancer discourse and the silence that I sensed (existent but unwritten) when analysing the texts. It would seem noteworthy that a particular silence also has significance in the context of the healing drama as practised in healthcare institutions. The reasons for doctors staying silent and distant may be interpreted as an unfortunate lack of personal ability, or as the result of an overlooked part of medical training:

*Samoin kirurgit eivät välttämättä ole maailman parhaita lohduttajia tai tukijoita; eräs tunnusti yhdessä luentotilaisuudessa: "Me emme tunnetusti ole maailman parhaita keskustelijoita!" Minun mielestäni lääkärin tärkein ominaisuus on kuitenkin*

*ammattitaito, mitään yli-ihmisen kykyjä heiltä ei pitä vaatia, mutta hiukan enemmän empaattista valistusta heidänkin taholta ehkä sopisi toivoa.*

The surgeons are not necessarily the world's best comforters or supporters; one of them admitted in one lecture: "As is well known, we are not the world's best speakers!" I think that a physician's most important quality is his or her professional skills, no one should expect from them the skills of a superhuman, but perhaps a little bit of empathic enlightenment could be wished from their side as well. (147)

Additional criticism considers the lack of time as due to the lack of human resources (024, 030, 046, 048, 061, 124, 125, 150, etc.). However the meaningful silence practised by medical professionals regarding cancer patients is also an interesting phenomenon from a cultural perspective.

Before the twentieth century the main institutions dealing with cancer were hospitals for the terminally ill (Porter 1999, 577). Because of social demand the situation changed and societies began to support cancer studies. Despite the enormous amount of funding spent every year on these studies, it has remained a misunderstood disease. Therefore, the reasons for doctors' distant behaviour and the silence described in cancer patients' writing may be linked to cancer's biologically complex nature. In biomedical terms all carcinomas arise or are initiated, and are then boosted by, gene mutations in single cells. Why such mutations take place is still under study and new ideas are proposed every year. These highly-valued explanations are incapable of offering treatments with definite outcomes. Therefore, I suggest that the silence practised in healthcare institutions may be seen as a result of a socio-historic development.

According to the biomedical paradigm, all assumptions and hypotheses must be capable of being tested and verified under objective, empirical and controlled conditions (Helman 2000, 79). Unfortunately for physicians, as well as for patients, the nature of every cancer is unique and its course unpredictable. Accordingly, the biomedical explanatory model for cancer simply lacks the requisite scientific rationality and therefore a significant cause of doctors' silence is their respect for the biomedical paradigm. As doctors cannot be scientifically rational and objective about the causes of cancer, they leave patients with no explanation, and patients do not understand it:

*Kysymys: Saitko tarpeeksi tietoa?*

*Vastaus: Ainoa (lue ja kirjoita: ainoa) pieni puute [sairaalassa] oli se, että tietoa ei tullut! Kyllä olisin monesti halunnut lääkärin suusta kuulla esim. suoritettavan kokeen*

*tarkoituspästä! Kuuluukohan "mykkyys" lääkärin etiikkaan? (Tuo ei nyt varmaan ollut sovelias kysymys.)*

Question: Did you get enough information?

Answer: The only (read and understand: the only) little problem [in the hospital] was that I got no information! I would have liked to hear from the doctor's mouth about the meaning of some procedures! Is being 'dumb' part of doctors' ethics? (This was perhaps not the most suitable question.). (060)

It seems that in order to protect patients from unfortunate misjudgements, doctors have adopted the idea that awareness about the possible causes of cancer, and suggestions about the expected course of the illness, cause suffering among the patients. This kind of myth forces cancer patients to study popular medical books, read various cancer booklets and search for additional information by themselves (Siponen 2003, 154). Individual judgements, based on unreliable sources and other patients' experiences, may lead to unfortunate misinterpretations and increase suffering. For someone who is not source-critical enough, the information that with his or her type of cancer the survival rate is 20% may be devastating. In the worst case such misleading information affects patient behaviour and individual decision making as it relates to personal health during the whole illness process. In such unfortunate situations, the doctor's role would be to explain that every statistical curve has a long tail, which indicates that many people continue normal life after cancer is cured (Servan-Schreiber 2008, 89–92).

The situation surrounding the silence within the medical paradigm is in fact quite similar to the popular discourse on cancer. The unique nature of cancer adds a great deal of uncertainty and pressure to any pathological drama relating to that illness. As no one knows its consequences, a patient's relationship with his or her doctor has a very important function in terms of feeling safe. The prospect of working in mutual understanding with physicians has a major significance for patients, who feel responsible for their own health. If doctors stay distant and silent, an individual's sense of being stigmatised only grows.

Cancer patients' writing represents a critical interface between themselves and the scientifically proven, rational, approach of modern biomedicine. Physician's surgical skills mean a lot to patients, but additionally they wish to be approached as individuals whose needs are integrated into the treatment process:

*Juuri lääkäreiden taholta saatava rohkaisu on ollut kiven takana. Tai oikeammin sanottuna sitä ei ole ollut ollenkaan. Ja kuinka kipeästi sitä tarvitaan psyyken*

*“jälleenrakennusvaiheessa”. Olen käsittänyt että vältetään väärän toivon antamista potilaalle. Jo käsitteenä “väärä toivo” on mieletön. Sitä paitsi toivottomuudessa eläminen vie lopullisesti ne voimavarat joita potilas tarvitsee selviytyäkseen joka päiväisestä elämästä. On ollut vaikeata kohdata se asenteellisuus, jolla liian helposti leimataan koko potilaskunta yhteneväiseksi ryhmäksi, ihmisiksi jotka sairastuttuaan vakavasti kokevat sairautensa ja sen tuomat ongelmat kaikki samalla tavalla. Jokaisellahan meistä on oma historiamme ja sairaudesta huolimatta olemme yksilöitä.*

The support from doctors has been concealed. Or to be correct there has been no support at all. And how much one misses it during the reconstruction of one's psychology. I have understood that they [doctors] try to avoid giving false hope to patients. The concept 'false hope' is mad. Living in hopelessness takes the rest of the energy that the patient needs to survive daily life. It has been difficult to face the attitude that stigmatises all patients to one singular group, to people who experience their illness and all problems caused by it in the same way. Every one of us has his or her lifestory and despite our illness we stay individuals. (195)

*Tunsin todella olevan yksin hätäni kanssa. Tuntui vaikealta palata hoitoja saamaan. Hoitoja vain annettiin, mutta itse potilas – juuri henkinen minä jäi hoitoa ja apua vaille. En kerta kaikkiaan enää olisi halunnut nähdä hoitajia enkä lääkäreitä. Ajattelin, että kyllä ne noita temppuja teknisesti osaavat. Osaavat laimennella sytostaatteja – pistellä niitä myrkkyyä meihin potilaisiin, mutta sielua he eivät pysty tai eivät halua hoitaa. /---/ Ei siinä potilaalle puhuta juuri mitään. Potilaalle jäi sellainen tunne, että olet vain tapaus: kylkiluu, keuhko, lonkka, umpisuoli – vain numero tilastoissa. Et ole tunteva, kärsivä, kuuleva potilas. Kenelläkään ei tuntunut olevan aikaa – ei uskaltanut kysyä mitään, kaikilla oli niin kiire. Potilas on hädissään, peloissaan, arka – et uskalla kysyä ja jos uskallat saatat saada hyvin ylimielisen vastauksen. Sain mielestäni hyvää sekä huonoa kohtelua sairaalassa. /---/ Olen usein ajatellut sellaisia potilastovereita, jotka hiljaa alistuen tyytyvät osaansa – esim. vanhukset tai muuten arat potilaat. Miten heidän käy? Jäävätkö he hoitoa vaille?*

I felt I was alone with my trouble. It felt difficult to return to be treated. Treatments were given, but the patient – particularly the spiritual self - was missing some cure and help. I just did not want to see any nurses or doctors. I thought that they know well all the technical tricks. They can mix the cryostats and put this poison into us, patients, but our souls they cannot or do not want to heal. [---] To patients they say almost nothing. Patients get the feeling of being a case: rib, lungs, hip, or appendix – only a number in the statistics. You are not a patient who feels, suffers and listens. No one seemed to have time – I did not dare to ask, everybody seemed to be in such a hurry. The patient suffers,



afraid, shy – does not dare to ask and when you do you might get an arrogant answer. I think I got both good and bad treatment in the hospital. [---] I have been thinking about this kind of cooperative patient, who shyly accepts their part – for example, old people or otherwise shy patients. How do they manage? Are they mistreated? (451)

Those patients who have experienced the desired patient-doctor relationship, describe the time spent in the healthcare centre and the treatments received as more rewarding than those who have been handled as diseased bodies. Thus, despite continuously increasing numbers of patients (cancer rates are increasing, partly thanks to facilities for early diagnosis) and enormous work pressure (also psychologically) doctors should still not forget that their patients are human beings, not only because of professional ethics but also because of better treatment outcomes. It could be claimed that the humanistic aspect of patient care is left to the nurses. Among their duties are both the “dirty work” as well as offering spiritual care (Widding Isaksen & Dahle 2000, 226–227). Notwithstanding, as doctors make decisions that concern the individual’s health, their empathy and time to talk is most valuable for patients as they have an urgent need for patient-doctor communication, and also a need to possibly negotiate individual aspects of their illnesses.

## **The power of healing narratives**

The material at hand, dealing with patients’ individual struggles with accepting the altered self in the context of treatments given in hospitals, makes me wonder how far can a human being go in accepting these alterations without losing hope, and more importantly, without losing the self entirely? In the case of cancer, the devastation and feeling of being stigmatised certainly relates not only to an individual’s body. The cultural stigma makes cancer patients feel equally insecure about their past behaviour and life. People with the cancer diagnosis often find themselves in a hopeless situation, without the opportunity of ever being ‘normal’ again. How is it possible to come out of this situation in order to regain the self?

Cheryl Mattingly suggests that patients suffering under the limitations of biomedical treatments have at their disposal a good tool with which to escape this misery. When faced with uncertainty and suffering, a common reaction is to tell a story. Mattingly proposes that “even when the pain is beyond words, when no story can be adequately told about it, a person may find that they draw upon narrative to remember and recreate a self, reaching

backwards and forwards in time in search of possible worlds, possible lives” (Mattingly 2004, 73). As a matter of fact, under such conditions any singular event may become significant for a patient’s recovery, while the experience that is indeed preserved in memory can be returned to, recalled, even reheard and re-felt.

Experience, when it emerges as a unique memory-making event, bears an ambiguous quality. It has some of the qualities of an object, inscribed in memory as a particular something that can be re-presented (Mattingly & Lawlor 2001, 33). Cancer patients’ writing proves that stories told, lived, and performed in hospital sustain a remarkable healing power:

*Munuaissyöpäleikkauksessa haava ulottuu melkein selkärangasta lähelle napaa – aika pitkä poikittaishaava tuosta vyötärön yli. Ja sitten, kun olin kertonut aamusella, kun pojan joukko soitti J:sta, että minulla on nyt tällöinen haava mahassa, niin poika sanoi sieltä, että “Äiti, nyt sinulle tulee ammatinvaihto: Sirkus Finlandiassa on sahatun naisen paikka auki”. Sen jälkeen olikin niin hankala olla, että oli siinä ja siinä ettei haava revennyt, kun nauratti niin kauheasti.*

The wound after kidney cancer surgery reached almost from backbone to navel – a quite long wound across the waist. And then in the morning, when I said to my son in J., that I now have this kind of wound in my stomach, my son said: “mother, now you must change your profession. In Circus Finlandia there is a place free for sawn women”. After that I laughed so much that I was lucky the wound did not open again. (072)

*Nyt minulla oli kuitenkin peruukki ja vedin sen päähäni, ennen kuin aviomies saapui. Mies tuli ja jäi ovelle katselemaan minua. Koetin tiiraila häntä, miksi ei tule huoneeseen, vaikka tunsin hänen hahmonsa ovella ja käytävällä jo kuulin hänen puhuvan hoitajan kanssa. “Mikä sinulla nyt päässäsi on?” mies kysyy ihmetystä äänessään. “Uusi peruukki, itseän tämän valikoit.” “Ei se tuommoinen ollut.” Otin peruukin päästäni ja sormeilin sitä. Mies tulee ja ottaa sen minulta ja nauraa sitten makeasti: “Tämä oli sulla äsken väärinpäin päässäsi.”*

Now I had the wig, and I put it on before my husband came. My husband came and stopped on the doorstep to look at me. I tried to look at him to see why he does not come in, although I sensed him being outside the door, and I had heard him talking with a nurse. “What exactly are you wearing on your head?” my husband asked with a surprised sound in his voice. “New wig, you chose it for me.” “It did not look like that.” I took the wig and let it through my fingers. My husband came and took it from me and then sweetly laughing told me: “You had it on the wrong way around.” (434)

In the hospital setting the act of storytelling has several meanings. Narrative is a reliable tool for exposing individual qualities. People may choose what they want to say and how they do it when introducing the self into the new surrounding. This is beneficial in order to become a member of the temporary community of sufferers. On the other hand, verbalising personal suffering and loss is a significant part of the patient's inner negotiation process and is necessary in order to accept the altered self. Sharing and telling stories is an important act particularly because the performed narratives may be recalled and newly imbued with meaning while the illness process is still in motion. Even when the pathological drama is over, significant personal experiences, captured as narratives, are stored in people's minds and may be reproduced. According to the cancer narratives, the process of recalling the experienced events via narration may be extremely rewarding. Which is to say that, narrated experiences give new meanings to the experiences gained in hospital.

Although the support of other patients, family members and friends may help to overcome individually critical situations, it is necessary to remember that the healing event performed between doctor and patient is still the most central to the hospital drama. Cancer patients' writing indicates that those moments when a physician comes closer and acts almost like a human, mean a lot for patients (079, 124, 125, 150, 435), even if the general health condition, based on rational reasoning and biological evidence, is totally unpredictable:

*Keväällä saimme osastolle oikean hymypojan, lääkäri M:n. Hän jäi usein juttelemaan potilaiden kanssa ja muistan tapauksen, kun meitä oli sattumoisin kolme urheiluhenkistä miestä. Toiset minua nuorempia hoidettavia. Möykkynen jäi hetkeksi taas hymyillen keskustelemaan. Ihmettelimme sitä, että miksi syöpä voi tulla, vaikka meistäkin jokainen urheilun avulla haluaisi pitää itsensä terveenä ja hyvässä kunnossa. Möykkynen kuunteli hymyillen tapansa mukaan ja rauhallisesti sitten louhii lausumaan. "Niin, siinä on hyvä otos ja näyttö, että urheilu on vaarallista." Hänen kanssaan ei voinut kuin olla samaa mieltä.*

In spring our department got a really merry doctor. He often stayed to have a chat with patients and I remember a case where there were three sporty men together [in the hospital room]. The others were younger than I. The doctor stopped again, smiling, to have a discussion. We were wondering how cancer may come, even if everyone of us had tried to keep themselves in good condition by practising sports. The doctor listened smiling

typically to him and calmly told us: “Well, there you have a good example of the dangers of sports.” There was no other way than to agree with him. (100)

Talking, sharing and storytelling have a practical quality during the healing drama. Accordingly, I suggest that performing ‘healing narratives’, interpreted as a sign of being human, is a good opportunity to establish the equality and trust desired in the patient-doctor relationship:

*Toivoisin lääkäreiltä psykologista silmää ja joustavuutta. En pidä vähätellä parantajan persoonan vaikutusta. Usein on niin, että lääkärin sanat saavat suhteetonta painoarvoa. Sitä kummastelee että tuo tietää kuolenko pian ja hänen vallassaan ovat hoidot, jotka siitä vielä pelastaisivat. Usko siihen että tehdään yhteistyötä ja selvittään voisi merkitä paljon.*

I wish doctors had would have an eye for psychology and some flexibility. The healers personality should not be underestimated. Often doctors’ words gain too much value. Then you must wonder if this one knows that I am going to die soon and in his hands are also the cures that could still save me. The belief that we cooperate and survive could mean a lot. (453)

From the ethnomedical perspective the primary arrangement for performing a successful healing ritual is if patients and doctors find themselves in an equal position or level. Foremost, this means reducing the cultural difference between physician and patient (Honko 1994, 37). Reduced inequality is very important in order to create the therapeutic relationship with the patient. This means that patients may trust and relay their health condition and individual concerns to the doctor without hesitation. And thus, both participants, patient and doctor, are actively involved in the healing drama.

Beyond all restrictions set by cancer’s biomedical paradigm, doctor and patient have to communicate in order to search for satisfactory solutions. This kind of communication has to engage with a patient’s personal feelings, show a true interest in a patients’ personality, lifestory, and primary fears and concerns. This is the proper way to create ‘healing narratives’, which are performed during the time spent in hospital, and which also offer patients a valuable tool with which to replay their feelings, and also to give new value to future reminiscences.

## Conclusions

The way society deals with illness has an essential effect on the wellbeing of patients. If we look at the ecological history of illness, it can be approached as a certain kind of interaction between nature and human kind. If environmental conditions change, the overall picture of disease also changes (Kjærgaard 2000, 15). Some centuries ago leprosy, plague, malaria, tuberculosis and syphilis took thousands of lives in Europe daily. As these diseases lost their significance, they were listed in medical history as a victory for medicine. However, the ecological and social history of illnesses offers a different set of explanations about the change in picture of diseases during the past centuries. For example, the defeat of malaria in Nordic countries is not explainable as a medical victory. Endemic malaria disappeared almost without any preventative techniques being adopted. The newest biological studies suggest that the decline of northern malaria was connected with changes in social structure: farm houses were built differently and people no longer lived in extended families, which reduced the possibility of being infected (Huldén, Huldén, & Heliövaara 2005, 1–13). In the middle of the 20<sup>th</sup> century (at least for a short period) it seemed that biomedicine might be capable of handling all illnesses that cause suffering to humans. This illusion has vanished as AIDS, cancer, diabetes, multiple sclerosis, new forms of tuberculosis and malaria, and many other long-term illnesses make people suffer and die every day. Some of these illnesses are the results of ecological change, others can be connected with lifestyle: eating and drinking habits, physical exercise, work conditions and general wellbeing.

Every decade has illnesses that reflect the societal and cultural settings of the time. This could be called the collective destiny of mankind (Kjærgaard 2000, 24). Despite new biomedical treatments and techniques, people continue to fall ill with cancer. Even if, for some individuals, the treatments ensure health, it does not help the majority of mankind. The main reason is money, or to be more accurate, the lack of it. No society can invest so much money in a healthcare system that people can be cured according to their expectations. This could also explain why cancer patients' descriptions and stories about their time spent in hospital are so critical.

At the moment there is a discussion on the social provision of screening for prostate cancer. The main discussion question is how many people in whom cancer is discovered, could be helped, and to whom, with nothing other than temporary relief available, would a discovery cause unnecessary suffering. It has been suggested that men with cancer cells in

their *prostata* could live without any complaints into old age. Whereas when cancer is discovered and treated, only one man in a thousand can be healed (Petäys 2003). The discussion surrounding Prostate Specific Antigen (PSA) tests mainly has an economic and medical dimension: specifically, how much money can be provided, who should pay and what extra efforts would be required from medical personnel? The cultural and societal dimensions seem to be insignificant.

In previous chapters I have described what it means to be diagnosed with cancer and what it means to have it from the patient's perspective. In this chapter I pointed out that for many respondents even the time spent in hospital, which is the officially approved path back to health, does not offer the expected relief in a holistic sense. The situation is rather the opposite: many cancer patients suffer from radically changed physical conditions and a lack of attention. Rather than feeling that they are being cured, they feel that they are being exposed in some way as individuals and then left alone with their feelings. From the cultural point of view, people seem to long for a more human approach particularly from their doctors, who are made responsible for the successful healing drama.

If our society has agreed on a particular path for the healing drama then this path needs a radical change, particularly in the areas of the patient as individual, and patient-doctor communication within the healthcare system. The treatments given in hospital are guided by doctors who represent the biomedical paradigm. Based on the cancer narratives I emphasise that among doctors' responsibilities should be support for cancer patients as individuals. Otherwise, patients perceive the healing drama as unsuccessful. Above all, this means that doctors should be interested in their patients as personalities. They should have not only the time, but also the interest, to listen to their patients' ideas, doubts and stories. Furthermore, physicians should have personal qualities that allow them to communicate with patients on an equal level in order to give patients the feeling of being safe and properly cared for.

## **8 Methods of Coping and Alternative or Complementary Self-Help**

When patients suffer from a lack of doctor's attention in the hospital they decide to search for self-help methods to become well again. The self-help methods selected are mainly those that complement the lack of attention towards patients' personal needs and desires. Active patients who wish to improve an unsatisfactory situation understand the need for self-help in order to cope with the situation and to find a way out in terms of recovery. These active patients try to regain control of their bodies and lives, and therefore search for various self-help methods to accomplish this. The self-help that cancer patients adopt may be connected with, for example, daily food intake or physical or spiritual exercise, which in general aim to give a more controlled and balanced life.

Cancer patients who entered the writing competition do not form a homogenous group of people. In everyday life they may have very different expectations of their own wellbeing and health. The conditions in which they lived was also dissimilar. Therefore, one should be aware that patients' abilities to cope with having cancer and to find suitable coping methods are dependent on numerous aspects. Normally the dominant expectations influencing the individual are expressed in writing, which naturally helps the interpretation process.

Above all, by adopting the role of active patient, people demonstrate their need to do or change something about their condition. This attitude is based on a very common belief, present in the cancer narratives, that if people do not help themselves, no one else can help them. This belief matches neither the expectations of the socially approved healthcare system, nor the doctors within it who expect people to give up control as they take on the role of patient. This makes the cancer patient's decision making, about how he or she makes use of the available domestic or alternative treatments, complicated in many ways.

In everyday practice, the dominant position of evidence-based medicine means that Finnish doctors concentrate on a patient's body and hardly ever suggest anything that does not belong to the category of conventional treatment. Studies have shown that about one or two percent of doctors recommend cures to their patients that are not biomedically approved. Even fewer doctors collaborate with other medical practitioners, such as zone therapists, chiropractors or folk healers (Hernesniemi 1991, 14–15; Hernesniemi 1994,

126–138). Public debate about the possibilities of implementing complementary and alternative treatments began at the end of the 1970s (Vaskilampi 1994, 227). These discussions were passionate and one-sided (Ryypö 2004). Looking back on that period, there was very little scientific argument about the potential of complementary and alternative healthcare, although it was evident that people made use of it (Meriläinen 1986). This also represents the current situation in the Finnish healthcare system.

In this chapter I will observe how Finnish cancer patients describe their use of complementary and alternative treatments as forms of self-help. I emphasise the cancer patients' reasoning about the use of complementary and alternative treatments in a situation dominated by conventional healthcare. Furthermore, I discuss the general meaning of debating the implementation of unconventional treatments as a path for self-help within the context of the cancer narratives. My suggestion is that the argumentation about various treatments may be interpreted as an important part of internal negotiation within narrative representations of the illness process (Lehmann 2007, 198–200). Foremost, its significance is in the prospect of regaining control of one's life. In addition to this, because of the almost underground position of complementary and alternative treatments, discussing opportunities for self-help represents a confrontation with the socially agreed conventions on cancer treatment.

## **Arguments regarding the need for self-help**

I use the concept 'self-help' to refer to all kinds of treatments and procedures that cancer patients find useful in order to feel, and become, better. Thus, a significant self-help method could be mushroom picking in the forest (033), drinking beetroot juice every morning (044), taking long walks (073) or sharing a moment of prayer with supportive friends (167). Although evidence-based medicine is seen as the dominant healthcare system in Finland, people are used to taking care of their own health, and thus primary healthcare is usually practised at home, before patients bring their concerns to the doctor's office. This could be interpreted as a part of modern health awareness, but also as culture-bound behaviour because all kinds of health concerns are initially handled at home. Such behaviour has its roots in tradition, in which domestic cures and healing practices were the most important means of becoming well.



As I have demonstrated in previous chapters, discovering cancer may be a long and complicated process, and thus the period before the diagnosis may be full of attempts to regain health using various products suggested by friends, available in grocery shops, pharmacies or specialist shops selling natural products (011, 031, 052, 059, 066, 085, 088, 102, 147, etc.). In the cancer narratives there is little about the use of traditional healing methods deriving from Finnish folk medicine for the relief of pre-symptomatic conditions. Common behaviour is for people feel who exhausted but have no other symptoms to take vitamins, minerals or natural products in order to become fit. When suffering pain they consume painkillers. If the complaint continues, people decide to visit the doctor. The pathographies used in this thesis show that the majority of Finnish patients prefer and trust conventional healthcare because it is the only healthcare system they know. Studies carried out in the 1980s and the beginning of the 1990s indicate that Finns used public healthcare services more eagerly than any other nation in the European Union (Koponen & Aromaa 2005). In contrast to the United States and some other European countries, treatment costs do not affect patients' decision making as public healthcare is state funded. On the other hand, recent studies have shown that the use of complementary and alternative treatments is rising among patients with long-term and serious illnesses, particularly as people are not satisfied with the treatments offered by the conventional healthcare system.

Cancer narratives demonstrate that almost immediately after the diagnosis of cancer, patients start to consider the possible use of complementary treatments. The cancer narratives show that when patients are not themselves interested in alternative treatments, there will always be plenty of friends, colleagues, acquaintances, other patients or even hospital staff who suggest non-conventional cures:

*Muutamat ihmiset neuvoivat minulle – varmasti ihan vilpittömässä hyvántahtoisuudessa – keinoja tautini parantamiseksi. Useammatkin tiesivät neuvoa nauttimaan erilaisia vitamiinipillereitä. Eräs kertoi itsellään olevan tuttavän, joka oli parantunut syövästään juotuaan muutaman viikon ajan joka päivä lasillisen elintarvikeliikkeestä ostamaansa eläimen verta.*

Some people advised me – probably wishing all the best in their hearts – all kinds of cures for my disease. Several people suggested different vitamins to me. Someone told me about a friend who got rid of his cancer [leukaemia] by drinking a glass of blood every day for several weeks. (233)

*J:n voinnista kiinnostuneet tuttavat atoivat minulle kaikkia neuvoja. Kouluterveysneuvoja oli myös tuttava naapuri. Hän neuvoi, että leukemiassa on auttanut neekerin veri, jos sitä veren siirrossa laitetaan, koska se on erillaista. Jotkut neuvoivat tuhkevettä (ymm).*

People interested in J's condition advised me of all possible cures. The local school nurse was also my neighbour. She said that Negro's blood had proved to be helpful in leukaemia if they make the blood transfer, because it is different. Others suggested birch ashes, etc. (011)

Accordingly, from the moment of diagnosis people are constantly faced with suggestions and proposals about unconventional treatments. Some patients see this as a natural part of their healing process, whereas for many patients the possibility of having another path to wellness represents a great individual challenge that is underlined by the cultural discredit usually attached to the use of alternative treatments. Despite the rising interest in alternative cures, people do not feel comfortable combining conventional medicine with complementary treatments. The cancer narratives tell us that the use of complementary and alternative treatments are taboo subjects for conventional doctors, and thus, any use of such treatments causes uncertainty and hesitation among patients:

*Mä pelkään aina, kun laitan jotain suuhuni tai kun en laita. Kirjoissa puhutaan asioista monin eri tavoin. Mä en uskalla syödä vitamiineja ja hivenaineita, vaikka uskoisinkin niiden vaikuttavan positiivisesti. Mä haluan mennä hivenainelääkärille.*

I am always afraid: either I put something in my mouth or I do not. In books they explain things in different ways. I am afraid of eating vitamins and minerals, even if I believe that they might have a positive influence. (087)

This means that patients who are not entirely satisfied with their treatment process at healthcare centre, or who want to improve their general health with the help of non-conventional methods, are often forced into situations in which they have to make use of complementary and alternative treatments in a secretive manner, thus confronting the social norm. According to the cancer narratives, the prospect of combining conventional and complementary treatments to improve a patient's health seems somewhat impossible to doctors (202, 230, 288, 335), although attempts to understand and find compromises would certainly be more beneficial (033, 059, 100, 205, 206, 275, 520). Some doctors even

force patients to choose: either use conventional medicine or go for alternative treatments. So, patients have to make the decision alone, and unfortunately in secret, to avoid their doctor's annoyance (see also Hernesniemi 1987, 67):

*En tiedä miten muut syöpäpotilaat ovat kokeneet "sodan", jota viime vuosina on käyty virallisen- ja ns. vaihtoehtoisen hoidon välillä. Tuskin kuitenkaan olen ainoa, jonka mielestä kyseinen repivä keskustelu on vain lisännyt paineita ja epävarmuutta potilaiden keskuudessa. Osalla meistä on luullakseen hyvin hatara käsitys siitä, mitä nimenomaan vaihtoehtoinen syövänhoito pitää sisällään. Tilanne on johtanut siihen, että "normaalien" hoitojen lomassa nautitaan joku vitamiinipilleri päivässä ja kannetaan huonoa omaatuntoa moisesta lipsumisesta kielletylle alueelle. Miksi ihmeessä näistä asioista ei voida hoitoyksiköissä avoimesti keskustella potilaan kanssa!*

I do not know how other cancer patients have survived the 'war' that has been taking place between conventional and alternative medicine over the last years. I doubt I am the only one who thinks that this passionate debate has only added to the stress and uncertainty among patients. Some of us have no idea what alternative cancer treatment means. This has lead to a situation that sees people take few vitamins and feel bad about sneaking to forbidden grounds. Why on earth can these aspects not be discussed openly with patients? (195)

The given example, in a similar way to others, highlights the urgent need to discuss the use of complementary and alternative therapies more openly in order to avoid the psychological pressure caused by secretive use of unconventional treatment. Some openness would have a positive result for doctors as it would help to avoid possible harm caused by combining biomedical therapies and complementary treatments. This is particularly true once patients leave hospital and become responsible for their own health once they are out of hospital. This means that theoretically people may decide on any suitable self-help method, even contradicting the doctor's prescriptions. Above all the possibility of making decisions about their own health makes people feel relaxed and satisfied:

*Päivä päivältä voin paremmin ja 13. päivänä leikkauksesta lähdin lomalle etelään mukana unitabletit ja särkypillerit. Kertaakaan en nauttinut niitä, vaan otin mieluummin lasin valkoviiniä aterialle ja huomasin, että olen iloisempi ja rentoutuneempi kuin ainaisessa "pillerihumalassa".*

Day after day I felt better, and on the 13<sup>th</sup> day after surgery I went on vacation with sleeping pills and painkillers. I did not use them, but preferred a glass of wine. I noticed that I am happier and more relaxed than when being ‘poisoned by pills’. (137)

*Hemoglobiini oli leikkauksen jälkeen 108. sen katsottiin olevan normaali, mutta hain kohta kotiin päästyäni apteekista rautaa.*

My haemoglobin was 108 after the surgery. They said it was normal but as soon as I went home I bought some iron pills from the pharmacy. (140)

*Aloitin taistelun kuntoni suhteen. Join esim. jotain männynuutejuomaa 2 000 mk:n edestä. tilasin sitä jostain Keski-Suomesta aina satsin ja koin mielestäni sen erittäin vahvistavaksi. Samoin tuhkalipeää join useamman vuoden ja nautin vitamiinipillereitä. En tiedä, auttoivatko em. asiat paranemiseni, mutta toivoa ne antoivat.*

I began to fight for my health. For example, I drank some kind of extract made of pine-tree that cost 2 000 marks. I ordered it from Mid-Finland and felt it to be really empowering. For several years I also drank birch-tree ashes in water and took some vitamins. I do not know if these things helped my recovery, but they gave hope. (542)

Thematically, cancer patients’ narratives give five general reasons for choosing complementary and alternative treatments. Firstly, patients feel that conventional treatment is somewhat insufficient: “*Virallinen lääketiede käski minun vain odottaa pari tuntia radioaktiivisen aineen imeytymistä, maata ihan liikkumatta puolisen tuntia, tulla kuulemaan tulokset viikon päästä...Kysymyksessä oli kuitenkin minun elämäni*”, “the official medical opinion was for me to wait while the radioactive substance sank in, lay without moving half an hour, come to hear the results in a week... It was after all my life” (202). The feeling of insufficiency usually begins when doctors ‘treat only cancer’ and leave the patient, as an individual, without any attention. Patients suffer physically and mentally because of their illness: “*Itseensä käpertyminen ja vaikeroiminen on pahasta, kyllä fyysinen ja psyykinen olemus kulkevat käsi kädessä*”, “being an introvert and silent is bad, indeed, the physical and spiritual self go hand in hand” (056). Patients worry about their work, family lives and the wellbeing of other family members. They are concerned about their futures. They analyse the reasons for their illness. If they find that something in their past was unbalanced, they want to fix it (066, 075, 088, 184, 318, 331, etc.). As

doctors concentrate only on cancer treatment, patients look for complementary cures that might help a holistic recovery.

Secondly, patients feel the urge to improve their condition in every way possible (052, 059, 085, 100, 125, 153, 322, 366, 542, etc.). They are concerned about their physical condition and think that their active participation in treatment should guarantee recovery. They study all the books about cancer they can find and analyse different materials available relating to their illness. They are ready to change their lifestyle for the better and therefore try everything that might be helpful:

*Kun vähän aloin toipua, tuli minulle valtava elämänhalu. Kyselin kaikilta tuttavilta syöpäpotilailta, mitä he olivat tehneet parantumisesna eteen. Luin kirjastosta kaikkea, mikä koski syövän hoitoa kotikonstein. Otin selvää ravintoasioista. Sain yksityislääkäriltäni hiven- ja vitamiinipillerit. Kävin tutustumassa elävän ravinnon kasvattamiseen. Laitoin viher- ja punajuuri mehut. Kasvatin ituja ja versoja. Kuuteen vuoteen en syönyt lihaa. Ainoastaan kalaa- ja vihannesruokaa.*

When I recovered a little I got such an urge to live. I questioned all my fellow cancer patients about what they had done to help themselves. I read everything available from the library that dealt with the domestic care of cancer. I understood things concerning food. From a private practitioner I got some minerals and vitamins. I went to see how to grow macrobiotic food. I prepared vegetable and beetroot juice. I grew cereal germs. For six years I did not eat meat. Only fish and vegetables. (044)

Thirdly, patients feel desperation and weakness caused by conventional medicine's sometimes radical treatments. For example, chemotherapy makes patients nauseous and weak. Patients lose their appetite and lose weight, lack energy, and finally their desire to live. In this case, alternative therapies are used as first aid to get back the appetite and with it the will to continue:

*Ylilääkäri kysyi minulta oliko kipuja. Eihän niitä ollut, kun vain pääsisin pahoinvoinnista. Jospa saisin puolukkaa, niin varmaan tokenisin. Neuvoteltuaan leikkauksen lääkärin kanssa, määräsi ylilääkäri minulta pois kipulääkkeet, ja kehotti kokeilemalla puolukalla oloni parantamista. Myöhemmin saatiin selville, että olen yliherkkä morfiinille. Puolukalla olin aina kotona saanut pahoinvointini pois ja ruokahaluni kasvamaan. Ja siitä tuli parannuskeino nytkin.*

The senior physician asked if I had pain. I did not, but the nausea was a problem. If I could get some whortleberries I would surely get better. After having a talk with my surgeon the senior physician denied my pain-medication and told me to try with whortleberries to make myself feel better. Later I heard I was allergic to morphine. With the help of whortleberries, I have always got rid of the sick feeling and improved my appetite at home. And this was a cure in itself. (205)

*Tuli maanantai ja tuli tiistai ja akka vain oksensi. Mitään ruokaa ei enää tehnyt mielikään. T., aviomies, haki sitten kaupasta ykkösolutta eli pilsneriä ja sanoi "otappas tuota, joku sanoi sen olevan hyvää huonovointisuuteen." Join sitä ja itkin, se oli mielestäni kamalla juotavaa. Se kumminkin piristi ja ei tullut enää ulos. Voin jo vähän syödäkin, aloitin sillin palasesta. Joten oli siinä "elämän eliksiirit" suolasilli ja ykköskalja.*

Monday came and then Tuesday but this woman was only puking. Food had lost its taste. T, my husband, got some low alcohol beer from the grocery store and said "take some, someone told this helps against nausea." I drank it and cried, this was an awful drink. But it pampered me and I did not puke anymore. I could even eat something, and I started with a piece of herring. So there were my "elixirs of life" a salted herring and a beer. (268)

Fourthly, patients feel the need for change in their personal lives (009, 046, 079, 050, 098, 214, 265, etc.). Patients who have survived cancer, analyse the period of their lives before they fell ill. They look at past behaviour and want to make a new start. Anne Hunsaker Hawkins has noted that the myth of rebirth is central in many pathographies (Hawkins 1999, 33). This particular myth is also an important organising construct that concentrates on traumatic experience and personal change. That is why many cancer patients talk about life before and after cancer. Life after cancer is experienced as a new opportunity. People experience things they only considered before, change attitudes and manners, choose new hobbies and think more about their own wellbeing.

Finally, sometimes doctors declare treatments unsuccessful, or that the cancer has developed so radically that conventional medicine is incapable of helping. For those patients, complementary and alternative treatments signify the last hope. At this stage many patients have given up their desire for recovery and so complementary treatments become the concern of relatives or close friends. Relatives and friends are often

encouraged by the stories of miraculous recoveries. According to the cancer narratives, in some cases alternative treatment as the last hope has indeed been helpful:

*Sairaus eteni hoidosta huolimatta ja viimein marraskuun alussa vuonna ’79 lääkärini todesi hoidon tuloksettomaksi, joten ne lopetettiin. Lopullisen tuomion kuultuani eristäydyin kotiin odottamaan lopullista poislähtöä tämän maan kamaralta. /---/ Luin lehdestä dosentti Tallbergin immunoterapiahoidosta ja viimeisillä voimillani päätin vielä yrittää sitä hoitomuotoa. Pääsinkin tutkimuspotilaaksi heti joulukuun lopulla ’79. Lähdimme aivan nollapistestä taistelemaan ruumiissani riehuvaa sairautta vastaan. Sain ojentautua aivan kuin hukkuva viimeiseen oljenkorteen. Hoito rupesi päivä päivältä ja viikko viikolta tuottamaan tulosta. Fyysinen olemus kuntoutui, samalla myöskin henkinen minä uudistui. Jaksoin taas uskoa huomiseen, sen mukanaan tuomiin haasteisiin! Olen niin onnellinen, että olen saanut elää noiden kahden epätoivoisen vuoden jälkeen 15 vuotta täyttä elämää.*

My illness continued to spread despite the treatments and finally, at the beginning of November ’79, my doctor said that the treatments were not working, so they must stop. As I heard the final sentence, I closed myself into my home to wait for the final leave from this earth. /---/ I read from the newspapers about the immunotherapy given by docent Tallberg and with my last strength left I decided to try this cure as well. I got a place as a research patient at the end of December ’79. We began from zero to fight against the illness demolishing my body. I was my last hope. The treatment began to function day after day, week after week. My physical self got better and at the same time my mental self was recharged. I could believe in tomorrow again and in its challenges! I am so happy that I have had a chance to live 15 full-blooded years after those two years full of desperation. (295)

This kind of narrative, about miraculous recovery with the help of alternative methods, are rather popular in everyday communication. These stories are used to assure people that alternative and complementary treatments really help, even in the most dramatic cases.

## **Complementary treatments in use**

In the following table (Figure 17) I have listed the various alternative and complementary self-help treatments mentioned in the cancer narratives. As the border between

conventional and alternative medicine is constantly changing, the self-help treatments listed in the table were not, according to cancer patients, prescribed by doctors. In the narratives, the usage of vitamins and minerals is perhaps the most common alternative treatment. Today the consumption of vitamins and minerals does not belong to the category of alternative and complementary self-help, as this method has been accepted by evidence-based medicine as useful and made a part of cancer treatments. The same thing has happened to lymph therapy, which at the beginning of the 1990s was seen as an alternative method, while today it is suggested to breast cancer patients who have problems with swollen arms.

In order to capture the variety of treatments used, I have divided the cures sought into three analytical categories: biologically-based practices, mind-body medicine and energy medicine. These categories ought to reflect the fact that, as with the folk medicine of the past, today people combine numerous treatments, as their main concern is to be cancer free and recover from illness.

<b>Biologically-based practices</b>	<b>Mind-body medicine</b>	<b>Energy medicine</b>
Herbs: garlic, onion, linseed oil, pine needles, parsley, cabbage & rhubarb leaves, Tibetan mushrooms, nettles, etc.	Patients support groups: Support person Support groups Rehab campus	Bio-field therapies: Therapeutic touch Reiki
<b>Foods and Dietary Supplements:</b> Fast food, vegetarian food, raw food, macrobiotic food, birch tree ash, fruits and berries, beetroot & rutabaga juice, calf's brain, fibre, cereal germs, seeds, cognac & eggs, vodka-salt-water, light beer (against nausea). Forbidden: coffee. culinary therapy vitamins, minerals & anti-oxidants	<b>Prayer:</b> Individual Hospital/community priest Religious community Prayer healer, long distance healer	<b>Other supplementary therapies:</b> Lymph therapy Immunotherapy Rosen method Hydrotherapy or hydropathy
	<b>Other complementary self-healing:</b> Nature, sporting activities, positivism, yoga, meditation, pets, bibliotherapy, sound therapy, self expression	

Figure 17. Complementary and alternative self-help therapies used by Finnish cancer patients



As the alternative and complementary cures are divided to three categories, I shall discuss these in separate sections.

### ***Biologically-based practices***

The results indicate that all biologically-based practices, such as herbs, foods, dietary supplements, vitamins, minerals and antioxidants are very popular. Their biological impact and usefulness has been thoroughly analysed in Pertti Arkko's book *Syövän kansanlääkinnän menetelmät Pohjois-Suomessa* (Folk Medical Practices for the Treatment of Cancer in North Finland, 1986). From the ethnomedical point of view the main intention of these treatments is to purify and strengthen the patient's body in order to fight the 'outside intruder'. In a similar way to folk medical treatments, we find nothing that would 'destroy' cancer directly among complementary medicine. These self-help treatments are meant to support cancer patients and give relief for various physical concerns. For example, the usage of cabbage and rhubarb leaves originates in Finnish folk medicine. These and other leaves were commonly used to reduce infections in swollen places. The original objective of this kind of treatment was to 'pull out the illness'. The particular cancer narrative that describes such treatment contains a warning, as the respondent burned herself when placing fresh leaves on her naked skin (435, see also 031). This was because acids from fresh leaves in spring can be dangerous, particularly if placed on wounded or sensitive skin.

Nevertheless, it has been fascinating to discover the tracks of culture-bound reasoning in cancer patients' narratives, as this gives an insight into the discussion on self-help and alternative treatment. One interesting idea relates to strengthening the patient's blood, two examples of which are given at the beginning of this chapter: drinking animal blood and getting a transfusion of Negro blood. Also categorisable under the heading *similia similibus curantur* could be drinking beetroot juice, which should "turn the weak blood red again": "*Syö paljon punajuuria, niistä tulee punainen veri*" (474, see also 044, 275, 633). The use of garlic (or garlic extract) (066, 265) and onion (037, 410), are also evident as methods of blood strengthening. In traditional Finnish folk medicine the smell of onion and

garlic, like the smell of pine needles (246) or extract (542), was often interpreted as having a purifying effect.

Birch tree ash, the use of which originates from folk medical practises (011, 224, 246, 275, 282, 286, 349, 455, 542, 547, 565, 627, etc.), was employed to strengthen and purify the patient's body. The ash is a medicine that some patients prepare themselves, while others buy it in the form of pills from herbal remedy shops. Because the use of birch ash is widely discussed in cancer narratives, it is a good example of popular reasoning towards this and other complementary or alternative healing practices. As in other areas of life, there are two opposing parties, in this case those who are ready to try, use and suggest everything, and those who deny the possible help of such means. The majority of cancer patients, however, seem to be somewhere in between: they are ready to try, but they are not passionate about it:

*Liikuttavinta muuten oli sairauteni aikana, kun pääsin sairaalasta oli mieheni keittämässä tuhkalipeää minulle lääkkeeksi. Se oli kyllä hieno rakkaudenosoitus, mutta minä kehno vain nauroin, että siinä taitaa olla mukana rautaa ja hivenaineitakin. Meillä kun poltetaan kaikki vanhat, naulaiset laudanpätkätkin. Ei toki, hän oli puhdistanut saunan uunin ja hakenut puhtaita koivuja, se on puhdasta koivuntuhkalipeää. Joimme yhdessä ne lipeät, eikä siitä haittaakaan ollut.*

When I was ill the most touching moment was when I arrived home from the hospital and my husband was boiling birch ash for me. This was a truly beautiful sign of love, but I silly only laughed and said that there would be also some iron and minerals in it because we burn all old wooden pieces, even those including nails. No, he had cleaned the sauna oven and got some clean birch: this was clean birch ash. We drank it together and it did not harm. (627)

Drinking cognac and other strong alcoholic drinks also belongs to the strengthening category (see also 157, 205, 349). Cognac is typically consumed together with raw eggs in order to promote recovery:

*Taksikuski otti minut matkan varrelta kyytiin ja hän neuvoi minulle lääkkeen, joka vahvistaa ja pysyy sisällä. Hän ajoi viinakaupan eteen ja käski hakemaan konjakkia. Ja niin aloin käyttämään päivittäin lääkkeenä raakaa kanamunaa johon loraus konjakkia kyytipojaksi. Kontrollissa ihmettelivät, että sädehoidosta huolimatta veriarvot sen kun*

*kohoa, ja tunnustin mitä olen nauttinut, lääkäri myönsi, että se on ihan hyvä lääke, me ei vaan voida sitä määrätä potilaalle.*

The taxi driver picked me up and advised me of a medicine that makes you stronger and stays inside. He stopped in front of the alcohol shop and told me to get some Cognac. And so I began to use raw eggs with a nip of cognac every day. In the check-up they were wondering, as my blood rates were getting better despite the x-ray treatment, and then I admitted what I have used. The doctor told that this is a very good medicine, but unfortunately they cannot prescribe it to patients. (380)

### ***Mind-body medicine***

The use of food and dietary supplements has a common place in the advice about cancer that spread to Finland at the beginning of 20<sup>th</sup> century. Foremost behind these ideas the Finnish-Swedish doctor Are Waerland (1876–1955) may be recognised. Waerland published several books dealing with the theme of cancer which contain suggestions on food intake and life habits, both as prevention and cure. His most famous book *In The Cauldron of Disease* was published in 1934 (Waerland 1934). His main health suggestions regarding cancer prevention concern the idea that people may improve their immune system by eating raw food and paying attention to their digestion. Waerland suggests that cancer is a lifestyle illness that has much to do with profession and social status. Accordingly, gardeners and peasants living on farmsteads are far less confronted by cancer than fishermen, butchers and bar keepers, who inhale smoke, consume alcohol, and eat ‘dead’ food. The latter occupations are particularly affected by dangerous ‘antropotoxines’, which derive from the human body and make the air that those professions breath unhealthy (Waerland 1949, 34–38). To avoid cancer, or to become well again, Waerland suggests special diets that consist of raw food and milk products. According to his theory, eating fish, meat and eggs is particularly dangerous. Furthermore, people should avoid hot coffee and hot meals as our insides do not have the protective skin that our bodies do. Above all, people should take care of their ‘inner purity’ by taking care of their digestive systems so that the food will not get ‘stuck’ in the stomach for a long time, where it might cause dangerous infections (Waerland 1949, 163–165). Waerland and his followers, sometimes called the waerlandists, were convinced that in addition to a vegetarian milk diet, water therapy and an active lifestyle guarantee health (Lehtonen 2003). Apparently,

Waerland's theories have had immense impact on popular reasoning about healthy eating and living. Naturally, popular knowledge does not derive directly from Waerland's books, but initially from various newspaper articles and essays, and subsequently from writing that reflects similar ideas.

The following example, which describes events that took place in 1984, might remind us of legends of miraculous recovery, although telling such stories is not uncommon among cancer patients:

*Kotona olin vielä kauan todella huonokuntoinen. Minun piti myös ratkaista ongelma, miten tästä eteenpäin. Päättelin, että jos vielä otan sitä myrkkyä, menedyn siihen, mutta jos lopetan hoidon kesken, lopputulos on ihan sama, tieni vain saattaisi olla pitempi ja kivuliaampi. Yksi hoitokerta jäi jo väliin ja seuraavakin läheni uhkaavasti enkä vielä ollut tehnyt päätöstäni. En osannut. Vihdoin tajusin tuoda ongelmani Jumalalle. Pyysin, että Hän osoittaisi minulle sen tien, jota Hän halusi minun kulkevan ja niin selvästi, että ymmärtäisin. Juuri silloin ovikello soi ja samassa jo eteisestä kuului tuttu ääni: "Hei, onko täällä ketään kotona?" Eteiseen päästyäni sain käsiini Elsa Ervamaan kirjan Elävä ravinto ja pussillisen vehnäjyviä. "Ja nyt kokeilet tätä, kuului komento." Joskus Jumala vastaa todella nopeasti! Ja ihanasti. Ja vakuuttavasti. Vehnäjyvät olivat jo itämässä ja olin innolla opettelemassa muista Elävän ravinnon alkeita, kun sain kirjeen Kanadasta. Serkkuni oli huolissaan kuultuaan hoidostani. "Lopeta heti se solumyrkkyhoito ja etsi käsiisi tietoa elävästä ravinnosta," oli hänen kirjeensä ydinsanoma. Olin saanut vahvistuksen asialle. Kumpikaan näistä Jumalan airuista ei tiennyt verenmyrkytyksestäni. Sädehoitopkl:lla kerroin päätöksestäni: enää en ottaisi solumyrkkyä, vaan siirtyisin Elävään ravintoon. Lääkäri sanoi, että saan kyllä vapaasti valita, mutta noin suuri syöpä ei sillä parane. Saisin kuitenkin tulla takaisin milloin vain haluan ja kontrollissa kävisin säännöllisesti joka tapauksessa. Olin helpottunut. Olin pelännyt hänen suuttuvan. Alku oli hankala, kaikki piti opetella kirjan ohjeiden mukaan ja muulle perheelle piti tietenkin laittaa tavallista ruokaa. Kun myrkyt läksivät liikkeelle elimistöstä, se aiheutti väsymystä. Paino putosi jatkuvasti. Monta kertaa olin niin uuvuksissa, että aioin lopettaa, mutta aina silloin joku ystävä toi jonkun uuden kirjan ja rohkaisi jatkamaan. Vasta syksyllä voimat alkoivat vähitellen palautua. Jaksoin käydä kävelyllä ja voimistellenkin kuntouttaa jalkaani, oikein paneuduin itseni hoitamiseen. /---/ Kevättalvella hiihtelin ja kuntoni kohosi. Söin dieettini lisäksi vähän voileipää ja painoni nousi 53 kiloon. Keväällä, vuosi elämänmuutoksen jälkeen pyysin lääkäriä mittaamaan kasvaimeni koon. Hän ei löytänyt sitä enää. "Siihen voi olla kaksi syytä," hän kiirehti selittämään. "Ensinnäkin, syöpäsolut ovat voineet kuolla jo sytostaattihoitonne aikana ja sen jälkeen elimistö on pikkuhiljaa poistanut ne kehosta.*

*Toinen syy saattaa sitten olla se elävä ravinto. Yllättävän hyvin joka tapauksessa on mennyt!*

At home I felt sick for a long time. I had to make a decision about how to continue from here. I decided that if I take more of this poison, I will die from it, but if I stop the treatment the result is exactly the same, my path could be perhaps longer and full of pain. I had missed one treatment already. The next was coming closer and I had not made up my mind. I could not. Finally I decided to share my problem with God. I asked him to show me the path that he wants me to follow so clearly that I would understand it. At the same moment the doorbell rang and from the hall came a familiar voice: "Hi, is there someone at home?" As I got to the hall, I was handed the book written by Ella Ervamaa: *Living Food and the Sack of Seeds*. "And now you will try it," I heard the command. Sometimes God answers really fast! And in a nice way. And in a convincing way. I had already planted the seeds and was studying other things regarding living food when I received a letter from Canada. My cousin had heard about my treatments and was concerned. "Stop immediately taking this cell poison and find out everything about living food," was the main message of her letter. I had received a confirmation of the issue. None of those messengers from God knew about my blood poisoning. In the hospital I told them about my decision: I will not take chemotherapy any more and will continue with living food. The doctor told me that I can choose freely, but such a large cancer will certainly not be cured like this. I was expected to come back whenever I wanted and I should visit the tests regularly anyway. I was relieved. I was afraid that the doctor would be mad at me. The beginning was difficult as everything was done according to the instructions written in the book and the rest of the family expected to get their normal meals. As the poisons began to leave the body I felt tired. I lost weight. Several times I was so exhausted that I decided to stop, but then some friend again brought some new book and encouraged me to continue. Yet, in the autumn I felt the strength coming back into my body. I had the power to walk and make some exercises with my foot. I was dedicated to taking care of myself. /---/ In winter I went skiing and I got fitter. In addition to my diet I ate some sandwiches and I put on some weight. In spring, a year after the big change, I asked the doctor to measure the size of my growth. He did not find it anymore. "There may be two reasons," he eagerly explained: "First of all the cancer cells died already at the time of chemotherapy and then your body has removed them slowly. The other reason could be the living food. Anyway, things have gone surprisingly well!" (520)

From the cancer narratives we find numerous similar success stories about the results of self-help. As these stories are represented in the cancer narratives, they take on another

significance as well. Unlike the legends of miraculous healing that are normally presented without extended context, entrants to the writing competition admit that such a big change in life can be really exhausting and time consuming. Although many people agree that the change has a positive impact on their bodies, finding and preparing appropriate food takes lots of effort. As with the story quoted above, the decision to give up biomedical treatments is not easy, whereas combining the two methods seems impossible. The first reason is connected with the societal expectation that every cancer patient should be treated in the hospital according to the socially accepted healing traditions of scientific medicine. The second reason is that various alternative therapists demand an immediate stop to biomedical treatments. The final decision makers, under such circumstances, are naturally the cancer patients, who generally expect something less radical, hoping to combine both methods to achieve a positive outcome. However, when the alternative path is chosen, which is normally after the biomedical treatments are finished or if they are unsuccessful, people admit that after some time they tire of it and return to their normal lifestyle and eating habits, although they perhaps pay more attention to what they consume (006, 018, 033, 037, 044, 066, 100, etc.).

### ***Energy medicine***

When discussing the reasons for falling ill, people often made a link with their individual thinking and behaviour. In order to become well again, they try to think more positively and do things that would bring some positive energy into their lives (046, 056, 125, 184, etc.). This could be described as attempting to balance one's psychological concerns. However, the means to achieve the desired balance can be widely different. The treatments of energy medicine resemble the aims of mind-body medicine. People search for lost vitality. The necessary energy may be received via healing hands, anointing rituals or by calling a long distance healer. Different supplementary therapies offered by various licensed and unlicensed practitioners come under the heading of energy medicine. According to the pathographies studied here, the main advantage of the various supplementary therapies is that practitioners take their time to care for patients holistically, considering both the physical and spiritual concerns. Naturally, such support may also come from any person who has a special relationship with the cancer patient: *“Uskon, että paras lääke sairastuessaan on toinen ihminen ja usko vakaa ajatus että paranen ja*

*haluan*”, “I believe that the best medicine if one has fallen ill is another person and a strong belief that I will get better - and I want it” (046). In this vein many patients make use of cancer support, provided either by communicating with the support person or by visiting a rehab campus for cancer patients. Of similar importance are religious groups in which the patient is supported by individual or collective prayer:

*Mutta eräänä päivänä hän soitti minulle ja pyysi minua kanssaan ajelulle naapuripitäjään. Ihmettelin, kuinka hän saattoi niin kuumeisena ja huonokuntoisena lähteä sairaalasta. Hän selitti saaneensa lääkäriltä luvan. Vävyimme haki hänet ja menimme eräaseen rukouskokoukseen. Siellä hän meni horjuen eteen ja pyysi, että hänen puolestaan pyydetäisiin Jumalalta apua. Minä istuin penkissä ja olin rukouksessa mukana itsekin. Mieheni tuli mun luo ja silmät loistivat kirkkaana. Suu hymyssä hän kertoi tunteneensa, että kaikki syöpä lähti hänestä pois. Se oli valtava tunne, näin hän kertoi. /---/ Ruumiinavauksessa todettiin, ettei hänellä ollut mitään syöpään viittaavaa, sydän oli kutistunut. Siellä oli ollut nestettä paljon ja kauan aikaa, mutta sitä ei ollut havaittu aikaisemmin.*

One day he called me and asked me to join him travelling to a neighbouring county. I wondered how he could leave hospital being so ill. He explained that the doctor allowed him. Our son-in-law took him and we went to a certain prayer meeting. There he went trembling in front of all the people and asked them to pray for him and pray for God's help. I sat on my bench and prayed as well. My husband came to me eyes sparkling bright. Smiling he told me how he had felt cancer departing from his body. It felt great, he said. [...] During the autopsy they did not find any cancer. His heart had shrunk. There had been lots of liquid in it for a long time, but they had not discovered it before. (167)

Searching for additional spiritual power from religion and prayer seems to be common for many Finnish cancer patients (see also Ahmadi 2006, 47–50). This appears particularly significant in comparison to Estonian cancer patients. The latter rarely adopt the structures of Christianity in their cancer stories and interpret their illness more as individual destiny. For example, in the Internet forum for Finnish cancer patients the Christians and non-believers clearly form two groups who argue about their illness process using two different paradigms. For Christians, the pathological drama is also a path by which to negotiate their individual lives as Christians. If people trust that they have spent their lives in accordance with biblical truths, it becomes easier to accept the illness process. Others, who interpret

their lives as not having been lived in accordance with Christian thought, find the idea that cancer is God's punishment appears as terrifying. The fear and hesitation deriving from Christian thought is particularly meaningful in the narratives composed by older men. They hope for forgiveness, while at the same time are still concerned about their status after death, and therefore accepting the idea of dying is very complicated.

Because of the agricultural roots of the Finnish population, the countryside and forest as natural surroundings have a particular significance. This also means that to practice self-healing rituals, people return to the countryside and the forest in order to regain their lost selves. Accordingly, in numerous contributions to the writing competition people are sure that in the countryside they can enjoy nature and receive nature's balancing and healing power: "*Leikkaushaava aristi kyllä joka askeleella ja sienikori painoi, mutta luotin metsäluonnon parantavaan voimaan*", "the surgery wound was still really tender when I walked, and the mushroom basket felt heavy in my hand, but I believed in the healing power of the forest" (033).

Above all, searching for spiritual support from nature may be interpreted as an act of regaining one's lost identity. As comparing oneself with other people seems impossible, the forest and nature represent spaces where people can be as weak and wounded as they like, without being judged by others. Being in a natural environment does not heal immediately, but the possibility to face personal change within natural surroundings is often represented as a key moment in understanding the central role of self-help:

*Tehtyäni aikani tätä surutyötä – ajattelin, että eihän tämä tästä ainakaan tällä tavalla parane vaan rasitan vain itseäni. Joten päätin että nyt on otettava itseään niskasta kiinni ja ryhdistyttävä. Aivan ihmeen kaupalla näin valoa elämässä, ajattelin niin kuin aiemmat potilaani, että tämä kuuluu minun elämäni joka ei ole omissa käsissäni, siinä välikädessä ovat lääkärit ja itse elämän antaja. Hyväksyin itselleni kummankin vaihtoehdon, joko kuoleman tai mahdollisen elämän jatkuvuuden, eikä se tuntunut ensinkään vaikealta tuon valtavan surutyön jälkeen.*

After mourning for a long time I thought that my life will not get better like this and I will only make my condition worse. Thus, I decided to get a grip on myself. As a miracle, I saw some light in my life. Like my patients before, I realised that this belongs in my life - which it is not in my hands. In between, stand doctors and the creator of life. I accepted both options for myself, either death or possible continuation of life, and it did not feel bad at all after such a long mourning process. (184)



## Basic concerns and problems with using complementary treatments

The public discussion about complementary and alternative treatments remains to this day either non-existent or very loaded. Therefore, we also find among cancer patients many who experienced complementary and alternative therapies as being somewhat problematic or ineffective. Cancer patients' reasons for choosing, or not choosing, complementary or alternative treatments is a good example of the public discussion, and of sociocultural attitudes towards non-conventional cures in Finnish society. Some patients are not satisfied with the fact that alternative treatments are not covered by health insurance. Others wish that they could openly combine various treatments. Above all, people seem very suspicious of the use of unconventional therapies, as during past decades they have learned that complementary and alternative treatments, like ethnomedical practices, are considered useless hocus-pocus. The following are some of the main concerns about non-conventional treatments, as expressed in the cancer narratives.

First of all, complementary and alternative treatments are expensive and time-consuming:

*Sädehoidon alkua odotellessa kävin vaihtoehtolääkärillä. Hän teetti erittäin laajan veritestin, sekä määräsi mahtavan määrän luontais/apteekki pillereitä, mutta ehdottomasti vain tukihoitona sädehoidon ohella. Tämä tuli kyllä aikalailla kalliiksi, koska sairaskuutus ei korvaa näitä kokeita eikä kaikkia lääkkeitä. Ehkä siinä oli hieman lääkärikin puolelta jo rahastuksen makua, joten en jatkannut käyntejäni hänen vastaanotollaan.*

While I waited for chemotherapy I visited an alternative doctor. He made very accurate blood tests and prescribed an enormous amount of natural and pharmaceutical pills. He said that these are meant only to support the conventional treatments. It was very expensive, as health insurance does not cover these tests and drugs. I was also left with the feeling that the doctor just wanted to make money, so I did not continue my visits to him. (066)

Secondly, complementary and alternative treatments cannot be openly incorporated into conventional treatments:

*Alkoi kamppailu elinajasta. HYKS:in hoito oli tehokasta ja hyvää. Omaisten voimavaroja ja alati orastavaa toivoaa riitti valitsemaan vaihtoehtohoidoksi kliinisen hoitomuodon rinnalle Kaarlo Jaakkolan vitamiini- ja hivenainehoito. Jäin kaipamaan HYKS:iinkin puolueetonta henkilö, joka voisi kertoa erialisista vaihtoehtohoitomuodoista, ettei yksittäisten sairaanhoitajien tarvitsisi kuiskalla niistä vaivihkaa, kun omaiset hädässään tiukkaavat kaikkea mahdollista apua rakkaalleen.*

I began to fight for my life. The hospital treatment was sufficient and good. Family and close friends wanted something more and so we decided to use vitamins and mineral therapy. I missed somebody at the hospital who was unbiased and could explain alternative methods to me – nurses should not whisper and hint about these treatments when people search for possibilities to help their loved one. (288)

Thirdly, complementary and alternative treatments are not reliable enough:

*Kaikenlaista luontaistuote parannuskeinoa ovat monet tutut ja lähes tuntemattomatkin suositelleet syöpääni. Yksi veljeni ja kaksi sisartanikin ovat soitelleet ja kirjoitelleet luontaishoidoista ja ihmetohtoreista jotka ovat sen ja sen saaneet parantumaan. Eräs kaukoparantajakin soitti (en tunne koko miestä) ja kysyi saisiko hän alkaa minua kaukoparantamaan. Eihän minulla tietenkään ollut mitään sitä vastaan. Mieli teki kyllä sanoa etten oikein luota sellaiseen hommaan vaan en halunnut loukata.*

Acquaintances and strangers alike suggested all kinds of natural treatments to heal my cancer. One brother and two sisters have called and written to me about natural cures and ‘wonder doctors’ who have healed various people. One long distance healer called and asked if he could help. I had nothing against it. I wanted to say that I do not believe in it at all, but I could not hurt his feelings. (508)

Fourthly, complementary and alternative treatments are not efficient enough:

*Sain kirjan itseparannuksesta. Kaikki ohjeet kelpaavat tähän tilanteeseen. Kokeilen kirjan oppia, panen käteni kipeälle paikalle ja sanon, parannu pian, parannu pian. Olen silti yhtä kipeä. /---/ Luonnontuotteet alkavat kiinnostaa minua, vaikka olenkin aina ollut oikein lihansyöjää. /---/ Saan uuden vihjeen, joka kuulemma on tunnetu*

*kansanparannuskeino kipeisiin paikkoihin. Tietenkin kokeilen myös sitä. Vihreän kaalinpään lehtiä pannaan kipeisiin kohtiin ja niinhän siinä kävi kuin olin uskonutkin, ei se mitään auttanut.*

I got a book about self healing. All instruction is useful in my situation. I try out what they suggest in the book: I put my hand on the ill place and say: "Become well soon, become well soon." I am still as ill as I was. [...] Natural products are interesting for me, even if I have eaten meat all my life. [...] I get a new tip that is a well known folk medical treatment against the ache. Of course I try it as well. I place green cabbage leaves on the ill place and it goes, as I believed – it did not help at all. (031)

Fifthly, complementary and alternative treatments are a marketing trick to fool desperate people and make money:

*On tietenkin helppo suhtautua kriittisesti näihin ilmiöihin, samoin kuin täällä hetkellä paljon esillä oleviin antioksidanteihin sekä vitamiini- ja hivenainehoitoihin kun oma kokemus koululääketieteestä on niin positiivinen. Voin kuitenkin kuvitella, että itsekin voisin takertua mihin oljenkorteen tahansa jos tilanteeni olisi toivoton, joten potilaita ei pidä moittia. Moitittavia ovat sen sijaan sellaiset piirit, jotka tietoisesti käyttävät hyväksi ihmisten hädänalaista tilannetta pelkän rahastamisen mielessä.*

It is easy to be critical towards these [alternative] treatments, as well as anti-oxidant, vitamin and mineral cures popular at the moment, if my personal experience of conventional treatment is so positive. I can however imagine myself using all available methods if my state was hopeless. Therefore, I think patients should not be admonished for using that. Rather, those who take advantage of people's desperation in order to make money should be admonished. (147)

However, even those cancer patients who have expressed real scepticism towards all non-conventional treatment still have some personal experiences, either negative or positive, of the subject. The discussion about the use of complementary and alternative medicine in cancer narratives emphasises the general need for openness concerning the use of complementary and alternative treatments. Beyond this need we may detect something even more important: the patient's need to be noticed, and treated, as an individual, rather than a non-human diseased body, during the illness process. As patients do not receive the

desired attention, they are prepared to go through the 'rites of passage' in order to get well as accepted on the societal plane.

Cancer patients' narratives show that people are rather bad at following health instructions when they do not find them useful or suitable to their condition. Something that applies both to following the biomedical instructions from physicians, and to the prescriptions of so-called 'vitamin and mineral doctors' and other alternative therapists, who in their private practices make blood tests and screenings and prescribe large quantities of pills that to improve cancer patients' general conditions (059, 268, 288, 569). Alternative and complementary self-help instructions from others may be seen as useful and be adopted with enthusiasm for a time; however, people often give up some time later. This happens mainly when they find out that to cope with cancer and have the strength to move onwards with their lives, they have to regain their previous trust in themselves. This also means believing in the self-help methods that feel good and, in the individual's opinion, help with recovery.

## Conclusions

The debate about choosing, or not choosing, complementary and alternative self-help methods, has a significant role in the cancer narratives. First of all, general discussion therein emphasises the role of an individual as a norm breaker or as a socioculturally stigmatised disease carrier. Secondly, cancer narratives point out the desire to be well again. Because the setting of the pathological drama is different for every cancer patient, there is also no consensus about using complementary and alternative treatments among them. However, cancer narratives indicate that people who have learned responsibility for their physical condition, appreciate the opportunity to be an active participant in the treatment process. Thus, as long as the conventional healthcare system continues to take care of dysfunctions at the cellular level, ignoring patient's other needs, people continue searching for complementary and alternative treatments in the hope of improving their health.

The main concern among Finnish cancer patients is their fear of discussing complementary and alternative treatments with their doctors. Medical practitioners, who are trained to trust only evidence-based medicine, wish to avoid the subject. This causes

concern and uncertainty among cancer patients, as in general they would like to agree with the doctor's expertise. Conversely, as people are used to taking care of their primary health concerns by themselves, they can decide to use traditional or non-conventional self-help therapies in addition to cancer treatments prescribed by doctors. Whatever the chosen treatment is, its aim is primarily self-help and ultimately recovery.

Above all, the use of self-help treatments among Finnish cancer patients indicates that illness cannot be separated from the person. The greatest benefit of non-conventional medicine is, therefore, that it does not concentrate only on curing cancer, but also on healing the sick person as a whole. This kind of need for a holistic approach appears to be very significant for cancer patients, who suffer not only from their illness but also from various domestic, work and relationship problems. According to the narratives analysed here, complementary therapies help people resolve their individual problems, they offer some of the support and hope for which patients so desperately yearn. In addition, cancer patients see the treatments listed above as purifying and energy providing. Occasionally, alternative treatments become a last ditch effort, either for the patients or for their friends and relatives.

## **9 Dream Narratives and How They Frame the Cancer Experience**

When examining the relationship between secondary and primary genres (see Chapters 1, 4 and 6) I noticed that, in cancer patients' narratives, dreams and dream-like images become interpreted as having particular significance. In Chapter 4, I suggested that dreams and dream narratives form a particular milieu within the narratives for expressing suppressed thoughts and fears. Furthermore, in some cases dreams and dream-like images frame the whole illness experience. Within the 672 pathographies under the study, I found 57 descriptions of patients' dream and dream-like experiences, which means that more than 8% of all participants shared some dream-related data. The real number of different narratives about the dream experiences of patients and their relatives and friends is almost twice as large. Quite obviously, people who experience dreams and omens have more than one story to tell.

Before moving to theoretical issues concerning cancer patients' dream imagery, it is important to note that dream narratives, in a similar way to the use of metaphoric expressions in particular contexts, are spontaneous accounts within cancer narratives. The announcement for the writing competition did not encourage participants to talk about dreams. Respondents who composed their stories and entered their dream accounts, obviously did so because they already felt that dreams had become significant during their illness process.

In the cancer narratives dreams and dream-like images become interpreted as events that take meaning from everyday life, particularly when they are connected with the illness process. Thus, dreams have significant meaning and position within the cancer narratives. Dream narratives are positioned either at the very beginning, or in the final chapter of cancer narratives. I argue that, in doing so, participants are emphasising the special character of dream events in comparison to those of waking life. Furthermore, sometimes dream imagery permeates the whole cancer narrative.

Several researchers have pointed out that in Western societies, discussing dreams in everyday communication is problematic (Kaivola-Bregenhøj 2000, 33; Tedlock 1992, 4). In my opinion, the great amount of spontaneous dream narratives within cancer narratives indicates the general attitude towards composing a thematic narrative based on individual

experience. I suggest that in composing their cancer narratives, respondents were delivering a private soliloquy, creating an intimate situation that allowed the discussion of issues that would be considered marginal – according to linguistic ideology or culturally defined discourse – in other speech situations. Bearing in mind the fact that the whole process of communicating cancer-related issues is understood as marginal, it would be useful to analyse the function and meaning of dream accounts in cancer patients' narratives. My main interest lies in questions of why and how dreams and images, as presumably uncontrollable events, received meaning within the context of a culturally marked situation such as having cancer. In other words, I wanted to observe how cancer patients interpret their dreams and associated imagery, and how these interpretations were integrated into the cancer narratives.

## **Dreams and dream-like images as events**

Dreams consist of heterogeneous elements and are often thought of as uniquely characteristic to human beings. According to popular understanding, dreams and dream-like images are defined as spontaneously occurring events. Spontaneous in that, in general, people are not able to control their dream imagery. Despite the fact that, in several cultures, we find specialists, such as shamans and healers, who are trained to produce and control dreams (Siikala 2002, 254–255; Price-Williams 1992, 247–249), in Western societies, controlling dreams is considered rather unusual. Therefore, dreams may be characterised as spontaneous events that occur under unintended circumstances.

Dreams reconnect us with the imagination, which is experienced throughout all modalities. In general, dreams and feelings are connected with the human ability to see, hear, smell, taste and touch. Dreaming is foremost a bodily experience that takes place in the brain. Very often, within this kind of experience there are all kinds of visual and auditory images. In Finnish, unlike English, people talk and write about *seeing* a dream or associated imagery (*näin unen*), rather than *having* one.

According to the cancer narratives, people may be awake or sleeping when dreams and dream-like images occur. Sometimes such imagery occurs shortly after going to bed or just before waking. Often people are not sure if they were actually dreaming or just daydreaming:

*En malta olla kertomatta sädehoidon loppuvaiheessa. Olinhan jo toipumassa sytostaattien vaikutuksesta, kun eräänä iltana mennessäni nukkumaan, koin erikoista. Olin kerennyt juuri petilleni ja vielä valveilla, mutta silmät kiinni. Koin, että silmämykiöissäni alkoi valkoinen piste laajeta. Ihmettelin, että mitäs nyt on tapahtumassa. En halunnut avata kuitenkaan silmiäni vaan annoin ”tapahtua”. Hetken päästä olin kuin ison valkoisen olotilan (pallon ) sisässä. Kuitenkin ”näin”, että oli vielä valkoisempaa: pieniä ristipistokoristeita kauttaaltaan sitä vaaleampaa tilaa koristamassa. Samassa näin kuin oikealla silmälläni soikean, poikkileikkaukseltaan hieman munan muotoisen putken. Se oli pinnastaan vihertävän harmaa ja kuin ristikudoskankaasta tehty. Putken sisään virtasi näkymätöntä nestettä, ikään kuin vettä, olematta silti sitä. Erehdyttävästi se muistutti väreilevää ilmaa. En halunnut avata silmiäni heti. Se oli ihmeellistä seurattavaa. Sitten se vain katosi ja tunsin silmissäni luonnollisen pimeyden. Avasin sen jälkeen silmäni ja totesin, etten ainakaan unta voinut nähdä. Sain kuitenkin unen helposti sen jälkeen. Seuraavana aamuna en puhunut vaimolleni ”näystäni” mitään. Tuli ilta ja menimme jälleen levolle. Suljettua silmäni, alkoi taas tapahtua se sama kuin edellisenä iltanakin. Olin katselemassa samanlaista valoisaa koristeellista tyhjyyttä. Yhtäkkiä näin nyt kuin molemmilla silmilläni, että näkökentän keskelle ilmestyi hiljaa pieni valkoinen pehmeä rengas: kuin jotain untuvaa tai senkaltaista. Se oli edessäni ja pysyen ”tyhjässä”. Sitten siitä alkoi tuikkia valkoisia ”purkauksia”, kuin auringon pinnassa tapahtuu, sillä erotuksella, että nämä tuikkivat rauhallisesti. Niitä oli useissa kohtaa rengasta ja ne työntyivät ulospäin ja vetäytyivät taas takaisin. Huomasin, että ne ”suihkut” osoittivat hoidettavana olevaa aluetta kohden. Näkemäni ei kestänyt nytkään pitkään ja hetken päästä oli samanlaista kuin eilisiltana. Avasin taas silmäni ja ihmettelin. Sain hyvän unen sen jälkeen. En vieläkään kertonut vaimolleni kokemastani. Kolmas iltayö alkoi samoin, kuin kaksi edellistäkin. Suljettuani silmäni, olin hetken päästä taas valkoisessa olotilassa katselijana. Nyt tuli kuin vasemman silmän puolelta nähtävää. Hiljaa näkökenttään ilmestyi kuin järven pintaa, mutta se ei ollut nytkään vettä, vaan sitä hiljalleen keinuva näkymätöntä väreilyä. Erikoista oli se, että siinä keinuivat hiljalleen kuin lumeenkukat, mutta väreiltään ne muistuttivat teräksenharmailta. Se oli kolmas perättäinen näkemäni ja ihmettelin niiden merkitystä. Nukahdin nytkin oikein pian. En kertonut vieläkään vaimolleni, vaan mietiskelin usean päivän ajan näkemistäni. Ne eivät nimitäin uusiutuneet enää. Tutkin kirjahyllystämme hallusinaatiosta ym harhakuvista, josko löytyisi jotain selvitystä näkyihin. En mielestäni ollut sen ”mielisairaampi” kuin koko elämäni aikana. Jotain muuta sen täytyy olla... Sitten aloin muistaa tapahtumia enne sairauteni ilmenemistä. Sairastuin löydettyäni 1989 oikeasta kaulavarrestani kyhmyn. Olin edellisen vuoden aikana, pitkin vuotta ”nähtynyt” oikean silmäni yläkulmassa ties kuinka monta kertaa kuin tumman pilven. Se ilmestyi ajoittain, olipa silmäni auki tai kiinni. Silloin*



*ajattelin, että tietäköhän se jotain sairautta... Kului kuukausia ja sitten tuo tumma pilvi muuttui molempien silmien nähtäväksi. Sain ikään kuin katsella suoraan, kuinka edessäni oli kuin sammakon kutua: harmahtavassa massassa näkyi mustia pisteitä. Nyt vasta palautui monien viikkojen jälkeen nämäkin. Olivatko ne enteitä tulevista tapahtumista? Siinä minulle olikin pohdittavaa. Sädehoidotkin olivat päättyneet toiseltakin erää. Sain luvan opetella uudestaan normaalia elämää... Sen jälkeen en ole nähnyt enää mitään, vaikka joskus olen ihan kuvittelut, että tuleekohan vielä jotain... Kaikki ne ovat kuitenkin pysyneet poissa.*

I cannot resist saying that at the end of my X-ray treatment, as I was recovering from the impact of cytostatic drugs. One night before going to sleep, I sensed something odd. I was in my bed and still awake, but with my eyes closed. I sensed that some white dot began to grow in front of my eyes. I wondered what was happening. I did not want to open my eyes and let the thing ‘happen’. After a second, I felt that I was inside a big white ball. However, I saw that there was something even whiter: little cross-shaped decorations decorating the light space. At the same time I saw with my right eye something oval; something like an egg shape cut into two halves like a pipe. It was greenish-grey on top and made from strips of cloth woven together. Inside, the pipe was dripping invisible liquid, like water but not water. It reminded me a lot of a shimmery air. I did not want to open my eyes at once. It was amazing to follow. Then it just disappeared and I felt in my eyes a natural darkness. I opened my eyes and was sure I could not be dreaming. Afterwards, I fell asleep easily. Next morning I did not say anything to my wife about my ‘vision’. The evening came and we went again to rest. When I closed my eyes, the same thing began again. I was watching a similarly decorated emptiness. At once I saw with both eyes that a little soft, white, circle appeared quietly: like a feather or similar. It was in front of me standing in the ‘emptiness’. Then little flashes appeared like the ‘explosions’ that take place on the sun, with a difference that these flashes were calm. These occurred in many spots on that circle and they came out and pulled back again. I noticed that these ‘bursts’ were pointing to the direction that was being treated. The vision did not last long and after a short while it was as the night before. I opened my eyes and wondered. Then I had a good sleep again. I still did not tell to my wife about my vision. The third night began in the same way as the other two nights. When I closed my eyes I was again in the white surrounding as an observer. Now the vision came from the left side. Slowly something like a lake appeared in my view, although it was not water but this kind of slowly moving shimmer. It was interesting that inside of it was like snowflakes, but their colour was steel grey. It was my third vision and I wondered, what was their meaning. I fell asleep again. I still did not let my wife know, but I wondered for several days what I had seen. These images did not come back anymore. I studied our bookshelves to find something about hallucinations and daydreams, to find

some explanation. I felt myself to be no more ‘mentally ill’ than I had been during my whole life. It had to be something else... Then I remembered the times before the illness came into my life. I fell ill in 1989 when I found a bump on the right side of my neck. The year before I had had ‘visions’ who knows how many times, throughout the entire year, about a dark cloud above my right eye. It came sometimes, either my eye was open or closed. Then I thought if it could mean some kind of illness... It took months and then this dark cloud came into both eyes. I could see straight into something that reminded me of frog’s spawn: I saw grey stuff with black spots. Now several weeks afterwards I remembered those again. Were these omens about forthcoming events? There I had something to think about. The second X-ray treatment circle was over. I had got the right to learn how to live the normal life... After this I have seen nothing anymore, even if sometimes I have even imagined that if there is something still appearing again... All these have stayed away however. (100)

Characteristic of dream events is that they are experienced mentally and physically, although the role of participant as sleeper, dreamer, or simply receiver, is passive within the unintended event.

Why dream events occur, or where they come from, is not apparent. Dreams may be defined as imagery created by an unknown source within the human brain. Adriëne Heijnen, an anthropologist and dream-researcher from Iceland, has suggested that dreams give insight into a world already present, but hidden from the waking person (Heijnen 2005). What I understand from this statement is that significant dreams appear first as hints within the background of dream imagery and later become connected to daily events.

Either consciously or subconsciously, people desire connections between dream events and waking life and through these connections to find out what some irrational events mean. Dream events receive their particular position in the flow of daily events via the interpretation process. People work through remembered dreams and perceived feelings while awake. Thus, dreams receive their meaning through an interpretation that is affected by the inner renegotiation process, lived experience and everyday communication. Accordingly, any conscious production of images is connected to the tradition of verbal expression. In this sense, it is essential that composed dream accounts (narratives) are not dreams (events), and neither narrating nor enacting dreams can ever recover the dream experience (Tedlock 1991, 162). In a wider sense, Barbara Tedlock’s statement concerns

any possible event that takes place in reality and its verbalised and interpreted narrative-reference.

## Making connections

The dreams and images that occur in the pathographies are presented as meaningful and significant references connected to personal life. Some dreams and images become interpreted as ameliorating and beautiful; others are distressing and even bizarre (Knudson 2001, 172–175). The psychoanalytical approach suggests that critical situations and social conflicts increase the amount of physical or emotional distress that will be transmitted into dreams (Wegner, Wentzlaff & Kozak 2004, 232–236). Therefore, dreams and other dream-like sensations should not be studied separately from the wider context. In this sense, the dream narratives that appear in the cancer narratives are a particularly good source with which to detect the function and meaning of dreams. Further, it is possible to follow the general concerns in respondents' minds and study connections arising in certain situations. We may learn that the prevailing concerns of cancer patients are illness and possible death, since cancer patients' dreams and feelings are tightly linked with illness and images of dying. Accordingly, the dominant emotions arising from dream events are connected with amusement, hope, confusion, distress and fear, all relating to the illness process and death.

Within any culturally agreed context, some people accept the role of active dreamer, while others feel themselves less able to perceive and remember dreams. The majority of cancer patients who describe their dreams, admit that they behave differently as dreamers in comparison to other people (066, 401, 411, 446, 520, 545, 563, 566, 582, etc.). These participants had discovered their ability to memorise dreams and make connections before they fell ill: "*Olen unennäkijä ja tiedän ja uskon että joskus niitten välityksellä viestiteään asioita ja tapahtumia*", "I have dreams and I believe that sometimes via dreams messages and things come though" (317). However, the cancer narratives also contain accounts in which the writer admits that dreams and dream-like imagery appeared as meaningful for the first time in his or her life at the time of the cancer experience. The following dream narrative exemplifies the fact that in a shared discourse, all people, both dreamers and non-dreamers, recognise the idea that dreams make connections:

*Olen pienestä pitäen nähnyt enneunia. Hyvin usein ne ovat toteutuneet. [---] Nyt aloinkin nähdä unia entisistä tiheämmin ja tiesin, ettei mieheni lähtöön ollut enää paljon aikaa. Ihme kyllä, kun nyt miehenikin alkoi nähdä unia, vaikka ennen hän sanoi minulle, ettei hän nukkumiselta jouda unia katselemaan. Eräänä lauantai-aamuna hän aivan tyynesti kertoi, että hänelle oli unessa sanottu, ettei häntä oikeastaan ole enää olemassakaan! [---]*

*Mieheni alkoi kertoa: "Mikä oli sen homman nimi? Makasin suurella laverilla, kukkien ympäröimänä. Huone oli kuin ravintola. Pöydät peitettyinä valkoisilla liinoilla, katettu ruokailuvälineillä. Myös kynttilöitä ja kukkia oli pöydillä. Siellä oli paljon ihmisiä, joita kaikkia en tuntenut tai en muista. Sinut ja lapset erotin joukosta. Tarjolla oli ruokaa ja kahvia. Tilaisuus oli juhlava. Siellä oli nuori miespappi, joka kävi täälläkin. Hän oli koko ajan minun lähettävilläni..." Mieheni kertomus sai meidät yhä enemmän hämmilemme, minkä vuoksi kyselin häneltä asioita tarkalleen. "Muistatko sinä papin käynnistä?" kysyin. "Muistan. Hänhän kävi äsken," mieheni vastasi. "Ei hän äsken käynyt, hän kävi aamulla aikaisin ja myöhemmin aamupäivällä toisen kerran," sanoin miehelleni. "Mikähän tilanne se sitten oli?" mieheni mietti ja jatkoi: "Se vaikutti niin aidolta." "Sinä nukuit vähän aikaa sitkeästi. Olisitkohan sinä nähnyt unta?" sanoin hänelle. Mieheni myönsi siihen, että niin sen täytyy olla. [---]*

*Tytöt kertoivat lauantai aamuna, että isä oli nähnyt yöllä unia. Hän oli puhunut unissaan ja puhe oli ollut harvinaisen selkeä. "Minulla on kiire," mieheni oli sanonut. Tytöt olivat kysyneet, ette mihin hänelle on kiire? "Pelastamaan ihmisiä," mieheni oli vastannut. Herättyään mieheni oli kertonut, että jossain maan vyörymässä oli hänen alleen sortunut paljon ihmisiä ja hänen täytyi auttaa ne pois sieltä.*

*Toinen uni koski sairauksia. Unissaan mieheni oli puhunut arpajaisista. Tytöt olivat taas kysyneet, että mitä siellä arvottiin? Mieheni oli vastannut: "Sairauksia."*

*I have seen predictive dreams since I was a little girl. They have come true rather well. [---] Now I began to dream more than before and I knew that there was not much time left for my husband. I was amazed, as he began to dream as well, although before he told me that he had no time to dream when he sleeps. One Saturday morning he said quite calmly that he has been told in his dreams that he does not exist anymore! [---]*

*My husband began to say: "What was that? I slept on a big sleeping board surrounded by flowers. The room was like a restaurant. The tables were covered with white cloth and dishes. Candles and flowers were also on the table. There were lots of people, I did not know or remember many of them. There was some food and coffee. It was a very fine event. There was a young male priest, who was here as well. He was next to me all the time ..." My husband's story made us wonder, and therefore I asked him, if he remembered the priest's visit? "I remember he was here a minute ago," my husband answered. I said to my husband, "No, he was not here, he was here early in the morning for a second time." My*

husband wondered, “What was it then?” and continued. “It seemed so real.” “You slept for a while deeply. Perhaps you had a dream?” I told him. My husband agreed with it. [---]

The girls told me on Saturday morning that father had had dreams in the night. He had been speaking in his sleep and the speech was seldom clear. “I am in a hurry,” my husband had said. The girls had asked, where to? “To rescue people,” husband had answered. As he woke up, he had said that in some earthquake many people had been trapped underground and he had to help them out.

The other dream was about illnesses. When dreaming my husband had mentioned the lottery. The girls had again asked what was the dream about? And my husband had answered: “Illnesses”. (157)

People experience dreams as events that may not be separated from the activities of everyday life. The interpretation of dreams is context dependent in the sense that dreams and images become interpreted as meaningful semantic or pragmatic references to everyday events (Tedlock 1991, 162). The interpretation process is based on individual experience and a cultural set of traditional knowledge. So, if we discuss verbalised dreams, we deal with texts that interpret the individually experienced events that perceive a meaningful image, according to the social value within the linguistic conversation and within the world portrayed. During this process, the dream narrative or prediction becomes a coherent message that may be represented within a communicative act.

## **Cancer patients’ dreams and dream-like images**

Dreams and dream-like images cannot become narratives without meaningful references to individual experience and cognition. In contrast to other human experience, dreams and ‘prophetic sensations’ are defined as unintended events. When people perceive these unintended events something happens. Accordingly, in dream accounts people describe what happened. Because of the internal negotiation or contextualisation process, particular dreams become significant within the framework of personal life. As people notice the relevance of certain events, they form an appropriate narrative that represents the lived experience. These narratives are composed according to the intention of a single author, but the result will never be free of cultural context. In this sense dream narratives are not isolated because they fulfil cultural, moral and genre-related expectations.

It is important to note that the dream narrative is not only about the received imagery. Typically, people describe unintended events in the introduction as the setting for the rest of the narrative. The complication includes references to events that occur while awake. In the conclusion, writers demonstrate how a dream event, or ‘omen’, came true either in real life or on the level of interpretation. As in the conclusion to any simple narrative, writers make their point or evaluate the whole narrative.

Setting	<p><i>Sitten näin unen, että oli joki jonka takana oli iso valkoinen rakennus. Joen yli johti kapea silta ja minä näin Saara serkkuni siellä sillan takana. Hän lähti siltaa pitkin luokseni ja minä lähdin häntä vastaan, mutta jostakin ilmestyi eteeni valkoisiin vaatteisiin puettu nainen ja sanoi: “Älä tule tämän sillan yli, siellä on perhonen joka lentää sinuun ja silloin sairastut samaan tautiin kun serkkusikin.</i></p> <p>Then I had a dream about a river and across this river was a white building. Crossing the river was a narrow bridge and my cousin Saara was on the other side. She came across the bridge towards me and I went to meet her. Suddenly a woman dressed in white appeared in front of me and told me: “Do not go there, there is a butterfly that will fly inside you and so you will get the same disease as your cousin.”</p>
Complication	<p><i>Heräsin ja mietin sitä unta, enkä saanut sitä pois mielestäni.</i></p> <p>I woke up and thought about this dream. I could not get it out of my mind.</p>
Solution	<p><i>Neljän päivän päästä siitä unesta sain serkultani kirjeen, jossa hän kertoi olevansa Korpilahden kunnalliskodin sairasosastolla ja sairastavansa syöpää.</i></p> <p>Four days after this dream I received a letter from my cousin. She wrote to me that she is in N. N. hospital and has cancer.</p>
Evaluation	<p><i>Kirjoitin hänelle unestani ja hän kertoi, että se paikka on juuri sellainen kun olin unessa nähnyt.</i></p> <p>I wrote to her about my dream and she said that the place [where she was treated] looked exactly as I had imagined. (105)</p>

This narrative contains several familiar dream symbols: a white building, a narrow bridge, crossing a river, a woman in white and a butterfly (see dream symbols in Kaivola-Bregenhøj 1986). These dream symbols provide the framework for a dream narrative, as

they represent culturally agreed dream symbols. Primarily, the dream symbol framework represents culturally accepted ideas adopted by the narrator.

As the dream image is so clear, the dreamer does not lose this dream but receives a vivid vision or other imagery that will be remembered and verbalised. Within the dream narrative, this imagery represents the dream events. As the story continues, it is possible to follow how the dream event receives its meaning and significance in waking life. Four days after this dream, the narrator receives a letter from her cousin, who reports that she has fallen ill with cancer. The respondent answers her and includes the dream imagery in her reply. Thus, interpretation of the dream continues and, as the dreamer hears that the place where her cousin is under treatment looks exactly as she had dreamed, it acquires new meaning.

As a matter of fact, the events described in this dream narrative took place in 1953. In 1994, when the writing competition took place, the respondent was over 80 years old. Although her cousin had passed away several decades before, she still had the urge to recall this significant and meaningful dream when discussing her own cancer experience.

Dreams are events that, as any other lived experience, may affect our internal reasoning and understanding of reality. During the verbalisation process, events become interpreted as significant and meaningful. Interpretation may take place as an internal negotiation, or as part of social discourse. Barbara Tedlock has delineated the clear difference between dreams as private mental acts, and dream accounts as public social performances (Tedlock 1991, 161). Similarly, Annikki Kaivola-Bregenhøj reminds us that “the narrative is far from visual experience, as when written down it becomes edited according to the rules of literary communication, made more concise and possibly clearer” (Kaivola-Bregenhøj 2000, 34). Although countless dreams are never presented as public social performance (Heijnen 2005; Heikkinen 2000, 297–302), it is important to remember that the interpretation of dream events is an ongoing process.

## **Interpreted imagery in the cancer narratives**

In the cancer narratives, some dream events are interpreted as prophetic, others as nightmares, while still others are attempts at solution seeking or amelioration. With the exception of omens (*enne, enneuni*) and nightmares (*painajainen*), dreams and images do

not have specific names in Finnish. Although a distinction is often made between different types of dreams, such as realistic dreams (*realistinen uni*), predictive dreams (*selvänäköuni*), true dreams (*tosiuuni*), or love dreams (*rakkausuni*) (Kaivola-Bregenhøj 2000, 34–35), the significance of the dream is actually detectable only when observing what references are made in the wider, secondary, narrative. During the verbalisation process people do not need to classify their experiences: the meaning of the events becomes clear during the communicative act.

Typically, most cancer patients' dreams are interpreted as omens, nightmares (solution seeking), or soothing (ameliorating) imagery. These dream types represent the interpretative meaning of cancer patients' dreams and dream-like imagery, although they also embrace the dream narrative's position within the cancer narrative. Prophetic dreams as omens are interpreted as catalysts for future events. Accordingly, narratives describing these images typically appear at the beginning of a narrative event chain:

*Isälläni oli tapana sanoa: Joka uniin usko, se varjoja pelkää. Sananlasku, jossa on tervettä järkeä. Unia en voi estää. Ne tulevat. Sama uni toistuu. Unissani on läsnä lapsi, pieni tyttö. Hän seisoo käsi ojossa. Vain oikea käsi on ojennettu. Koen olevani se lapsi, se tyttö. Unessa kuulen äänen. Kuka puhuu, mistä ääni tulle, millä kielellä sanat sanotaan? Siitä minulla ei ole aavistustakaan. Ehkä ääntä ei kuulukaan, ehkä vain tajuan sanoman. Se on minulle tuttu. Afrikkalainen äiti opettaa lastaan jo pienestä pitäen kohteliaaseen käyttäytymiseen. Siihen kuuluu tapa ottaa vastaan lahja. Lahja on otettava vastaan molemmiin käsiin. Yhdellä kädellä vastaanottaminen merkitsee lahjan väheksymistä. Hiljaisella äänellä ikäänkuin taustalla äiti ohjaa lastaan: Mikono miwili, mwanangu. (Kaksin käsin, lapseni). En tiedä, näenkö pienen tytön, itseni, unessa vai olenko vielä valveilla. Ehkä olen niin unen ja valveen rajamailla, etten osaa tehdä eroa. Jos herään täyteen tietoisuuteen, kuvaa katoaa. Jos uni syvenee, kuva samoin katoa. Mikä on se lahja, jota olen vastaanottamassa epäkunnioittavasti, vain yhdellä kädellä? Onko se tämä sairaus, tämä elämäntilanne?*

My father used to say: "Those who believe in dreams are afraid of their own shadows." It is folk wisdom based on healthy reasoning. I cannot avoid my dreams. They come. The same dream repeats itself. There is a child, a little girl. She has raised her arm. Only the right arm is raised. I feel that I am this child, this girl. I can hear a voice. Who is speaking, in which language? I have no idea. Maybe there is no voice and I receive only the message. I know it. An African mother admonishes her child about proper behaviour. It is about accepting a present. You accept it by raising both hands. If you raise only one hand it lessens the value of the present. *Sotto voce*, as in the background, she admonishes



her child: “*Mikono miwili, mwanangu*” (With two hands, my child). I do not know if I see a little child, myself, in a dream or am I still awake? Maybe I am between dreaming and waking, so I cannot tell the difference. When I wake to my full consciousness, the picture vanishes. When the dream becomes more intense, the picture vanishes. What is this present that I do not accept with full respect, with one hand? Is it this illness, this situation?” (330)

This dream account begins with the narrator’s representation of her background. She refers to her father’s rational wisdom. The father admonishes her for believing in dreams. However, despite the father’s words, dreams appear to the narrator and she cannot help it. In her interpretation the present becomes a symbol of her illness. Connecting the dream event with reality helps her in the process of accepting the idea of having cancer.

It is apparent from cancer narratives that nightmares, or solution-seeking dreams, and feelings of fear, emerge (repeatedly) during the illness process. Usually these dreams and images represent ongoing and unsolved events. The same narrator continues:

*Myöhemmin uneni muuttuu. Sekin toistuu. Kuljen kaupungin katuja. Maisema on oudon tuttu ja samalla oudon vieras. Se on aina afrikkalainen kaupunki. Siinä’ on piirteitä vanhasta kaupungista Zanzibarin saarella. Korkeiden talojen reunustamia kapeita mutkikkaita katuja. Joskus taas luulen olevani sisämaassa Mbeyan kaupungissa. Kuljen vuoren rinteelle rakennetussa slummikaupungissa, joka on levinnyt hallitsemattomasti. Olen aina eksyksissä. Kadut ovat sokkeloisia; ne saattavat päätyä umpikujaan. Joskus löydän torin. Lähdän liikkeelle torin varrelta. Pian huomaan kiertäneeni kehää ja palanneeni takaisin samaan paikkaan. Torin toisella laidalla saatan nähdä portin. Se on aina suljettu. Sen yläpuolella on jotain, jota en näe oikein tarkkaan. Se saattaa olla kirjoitettua tekstiä, jota en osaisi lukeakaan. Se voisi olla vaikka arabialaisia pitsikirjaimia. Kuljen aina yksin. Kaupunki on hiljainen, kuollut, täysin äänetön. Ketään ei näy, ei ihmisiä eikä eläimiä. Autius vallitsee kaikkialla. Edes linnut eivät laula. joskus joku ystävästä tulee uneen. Kuulen äänen, näen hahmon seisomassa taivaanrantaan vasten. Hän sanoo ehkä: Tule, on jo aika mennä kotiin. Joskus taas: Tule, lähdetään. Joskus ei ole ketään. Ketään ei tule. Herään hätään ja turvattomuuteen: Minne kaikki on kadonnut?*

Later my dreams change. This one also comes repeatedly. I wander around the streets in the city. The landscape is bizarrely familiar. It is always an African city. There are some aspects of an old city on the Zanzibar islands. Never-ending streets surrounded by high buildings. Sometimes I think I am in the city of Meyba. I stroll in the slum that is built on

the hillside and spreads haphazardly. I am always lost. Sometimes I find the market place. I continue, but soon I notice that I have walked in circles and returned to the same place. On the other side of the market place I see a gate. It is always closed. Above it is written something that I cannot read. It could be something containing Arabic letters. I am always alone. The city is quiet, dead, motionless. I see no one, no people or animals. Everywhere is emptiness. Even the birds do not sing. I can see a person standing near the skyline. Sometimes he says: 'Come, it is time to go home'. Sometimes there is no one. No one comes. I wake up in confusion and fear: Where is everybody? (330)

The new dream with its events appears repeatedly. In this dream the narrator imagines herself being trapped in the labyrinth of streets. Illness creates the feeling that there is no way out. The daily fears the narrator has because of her illness materialise in this dream event. The dream occurs several times during the illness process, which indicates that in her mind she seeks a solution without yet knowing the outcome.

Narratives that respondents portray as ameliorating appear typically at the very end of the cancer narrative:

*Unieni kuva torin takana olevasta portista tulee mieleen. Portin päällä on kirjoitusta, jota en osaa lukea. Jotenkin on kuitenkin tullut tajuntaani, että se kirjoitus on sana "PARANEMINEN".*

The picture of the market place gate comes into my mind. Above the gate is a sign that I cannot read. Somehow I subconsciously believe that the word "RECOVERY" is written there. (330)

The narrator interprets the meaning of a sign she has observed in her previous dreams according to her situation in life. In the final dream connected to her illness process, a significant word, RECOVERY, appears. In her written dream narrative she writes the word out in capital letters.

As cancer narratives are not written only by cancer patients, but also by their relatives and friends, there are, at least seemingly, slight differences between the dream imagery. Although they need more careful examination, the processing type of dream or nightmare is more typically experienced by cancer patients. Prophetic or ameliorating dreams appear equally to cancer patients and their loved ones. This may be explained by the fact that every cancer patient goes through the illness process individually. Others must accept the

role of observer regardless of how actively they take care of the patient and follow the illness process.

## **Dream narratives as paths for the expression of suppressed emotions and marginal themes**

The cancer narratives show that, because of their cultural marginality, discussing issues relating to illness and death is in many ways a challenging communicative act. According to the reasoning expressed in pathographies, the process of having cancer has two solutions: recovery or death. Therefore, predictive dreams and images are received as omens of impending illness or death, whereas ameliorating dreams and feelings arise as omens of recovery or messages from ‘the other side’. In comparison, interpreted dreams presented as narratives do not provoke such uneasiness. My assumption is that telling a dream narrative is easier than sharing suppressed emotions on marginal themes, both for the storyteller and the listener.

Under normal circumstances people do not discuss topics relating to death and recovery openly with cancer patients, or at least the discussion occurs with a certain uneasiness. Therefore thoughts about death and recovery could be classified as suppressed emotions in the context of the personal illness experience. Psychologists Wegner, Wenzlaff and Kozak have suggested that, although dreams sometimes contain “day residue” – direct echoes of prior waking experience – they might be more likely to include residue of thoughts that have been intentionally suppressed (Wegner, Wenzlaff & Kozak, 2004, 232). Accordingly, in cancer patients’ dream imagery we may detect an opposition typical to the illness process relating to cancer.

People who go through emotionally difficult times may employ their significant dream experience repeatedly, in this manner opening a path by which to share their concerns. Cancer narratives demonstrate that dreams repeated in narrative form may help patients to go through an emotionally complicated period:

*Koin samaan aikaan selittämättömän asian. Kun illalla kävin nukkumaan, tunsin koko sädehoidon ajan vuoteeni sivulla kuin korkean voimapatsaan. Olen aina tahtonutkin uskoa, että ihmistä ympäröivät hyvät voimat. Pitää vaan hiljentyä tunteakseen ne. Olen ikuisesti kiitollinen tästä kokemuksesta.*

At the same time I experienced an unexplainable thing. Throughout the X-ray treatments, every evening when I went to sleep I felt a power-statue standing next to my bed. I have always wanted to believe that people are surrounded by good powers. One just has to calm down to feel these. I am really grateful for this experience. (217)

Sharing feeling and thoughts with loved ones is sometimes very difficult. It is possible to observe, in the cancer narratives, how people who remember dreams and perceive omens gain, through dreams, an additional path that allows them to express suppressed feelings. The 'fixed' form of the narrative somewhat lessens the emotional weight and marginality that suppressed emotions and illness themes otherwise carry for listeners (Kaivola-Bregenhøj 2003, 330–332). I suggest that dream narratives are not taken so seriously by other parties, at least under normal circumstances. Thus, sharing dream and prophetic narratives is to some extent a subconscious way to process difficult feelings without placing other people in an uncomfortable position. Furthermore, I argue that in the context of marginal experiences, such as the traumas caused by illness and death, dream narratives function as valuable paths by which to express suppressed inner sensations and culturally marginal themes. In these circumstances it becomes significant that, when presented as narratives, the difficult emotions that emerge in dreams and are interpreted as dream narratives may be discussed and re-interpreted more than once in different situations.

## **The individual and cultural meaning of dreams**

Above all dreams and dream imagery have individual value. When analysing dreams and dream telling traditions, Finnish folklorist Leea Virtanen has noted that dreams are not only important in social communication. Suggesting that people also have an 'inner mind' tradition, Virtanen proposes that people may analyse their dreams themselves, re-experience feelings, interpret these dreams based on various memories, and above all reorganise the events of illogical dreams into an appropriate textual form. At the same time, dreamers must constantly analyse and verbalise dreams in their minds in order to understand what the meaning of a dream symbol is. At the same time, the narration is also constructed (Virtanen 1980, 65). Dreams represented in pathographies show that people are interested in the meanings of their dreams. After presenting her dream account, about snakes that were searching for a way out through her fingertips, one participant continues:

*Mietin monena päivänä unen merkitystä. Olen unennäkijä ja tiedän ja uskon että joskus niitten välityksellä viestitetään asioita ja tapahtumia. Tuota unta en saanut mielestäni, sillä se oli viesti jostakin. Eräänä päivänä “välähti”. Se tarkoittaa sitä, että minulla on paljon noita pieniä käärmeyä elimistössäni mutta minun “tarttee tehdä jotakin” itsekin, että saisin nujerrettua nuo virkeät nopeasti kasvavat syöpälauset.*

For several days I thought about the meaning of my dream. I have dreams and I know and believe that sometimes via dreams we get information and messages. I could not forget this dream as it was a message about something. One day it suddenly became clear. It meant that I have lots of those little snakes inside of my body and I must do something to make myself well so that I could get rid of those fast growing carcinomas. (317)

Young children are also able to receive and verbalise their dreams and images:

*Sinä syksynä kun A. samana kesänä sairastui hän tuli eräänä aamuna syliini ja sanoi nähneensä unta, jossa pappi yritti panna häntä arkkuun, mutta hän ei halunnut laittaa silmiä kiinni vaan tuli sieltä pois. Muistan kuinka lamaannuin enkä pystynyt puhumaan mitään. Sitten aloin miettimään, oliko tuo lapsi todella puhunut nuo asiat. Tuntui uskomattomalta, että 4-vuotias puhui tuollaisia asioita.*

In the autumn after the summer when A. had fallen ill, she came to sit in my arms one morning and said that she had had a dream in which a priest had tried to put her into a coffin, but she did not want to close her eyes and so she left the place. I remember how I lost my senses and I could not react to her story. Then I began to wonder if this child had indeed told such a story. It seemed unbelievable that a four-year-old could relate such an experience. (548)

From a cultural perspective, dream and omen interpretations are usually given by grandmothers and mothers, although Leea Virtanen has proposed that in earlier times men have also been dreamers and dream interpreters (Virtanen 1980, 56). Because in Nordic countries dream interpretation books have been in use for several centuries (Bregenhøj 1992, 187–272), people are familiar with the routine of using them to explain significant dream symbols. After surgery a respondent with lung cancer experienced a recurring dream:

*Näin monena yönä pikkulapsesta unta. Sanoinkin, että taas olin sen pikkuisen kanssa tekemässä jotakin. Unikirjasta selvitystä tähän hakiessani löysin vastausta: pikkulapsen*

*näkeminen tarkoittaa: elämän iloa. Sekin tuntui ihan hyvältä, tässä vaiheessa. Sitähän tässä tarvitaan.*

Several nights I had a dream about a small child. I also told others that I had something to do with the little one. When I searched for an explanation from a dream book, I found: seeing a small child signifies the joy of life. This felt very good at this stage. That was exactly what I needed. (302)

We also receive information about dreams and omens and their cultural interpretations through communication. References to a traditional set of dream and omen interpretations are as important as personal experience-based explanations. People learn and experience new interpretations during their lives. This is a continuous process in which people are open to new experiences. Cultural, as well as scientific, dream explanation and interpretation is controversial, although dreams and images are not insignificant. Individuals employ all available interpretations, and re-interpret and verbalise dreams into forms appropriate to be used in connection with other events and experiences. This explains why dream events also become a part of the cancer experience.

## Conclusions

(Discussing) having cancer is considered marginal from a cultural point of view. Foremost because it evokes strong emotions connected with illness and death. Therefore it is natural that the ideas regarding the illness process, recovery and death become suppressed in everyday communication. In this chapter I have pointed out the particular position of dream narratives within cancer narratives. I argue that pathographies form an excellent source from which to observe the spontaneous occurrence of dream narratives in connection with a particular discourse. Dream narratives begin with an event account but become interpreted in the wider context of daily events. This means that within the dream narrative the event appears only as the setting for the dream narrative. Under normal circumstances, people analyse their experience and verbalise it more than once. In this way it becomes an attempt to synthesise waking experience and dream experience into a significant whole.

Although cancer patients interpret their dreams according to individual understanding, it is possible to talk about three kinds of dreams. Firstly, respondents describe predictive dreams and omens, dreamt before falling ill or losing a loved one. Secondly, respondents

write about dreams and feelings that may be described as solution seeking dreams. Thirdly, participants write about ameliorating dreams, which occur either shortly after the illness is cured or the cancer patient has passed away. The significance of such experience is revealed by participants as they place dream narratives at the very beginning, or in the final chapter, of cancer narratives. I argue that the interpretation of dreams is very important as it is a way in which people may interpret and share suppressed emotions and thoughts without being labelled.

## **10 The Study of Written Cancer Narratives: Comments and Conclusions**

What happens when people are diagnosed with cancer? How do cancer patients cope with their illness and how do they manage their daily lives? To answer these and several other questions dealing with cancer I read and analysed 672 written narratives from the Finnish Folklore Archive, collected in 1994. Above all, the cancer narratives demonstrate that whatever the official medical explanation and treatment might be, patients come up with their own explanations and search for complementary methods of self-help to cope with their illness. In the patients' interpretations, the origins of cancer are connected to an individual's life and lived experience. This is an important concept that should be noted, for example, in order to establish a functioning patient-doctor relationship and to lessen cancer patients' suffering.

The patients' points of view seems significant as the written cancer narratives - short pathographies – differ greatly from the pathologies provided by socially approved biomedicine. Because of my approach as a folklorist, I have studied cancer patients' thoughts, experiences and feelings from the cultural perspective. However, it is difficult to draw any conclusions without thinking of the dominant developments in the social, political, economic and medical worlds, which have a significant affect on patients' positions in society. I suggest that observing the important changes in society from different perspectives shows how every historical era has characteristic illnesses reflecting the societal and cultural setting of the time. Furthermore, cancer narratives shed light on questions about the meaning of cancer at societal and institutional levels.

The cancer narratives studied in this thesis reveal patients' individual approaches to the challenge of having cancer, as well as various culture-bound beliefs, fears, myths and other significant ideological images about being ill. Thus, the writing sent to the folklore archive form a valuable ethnographic source with which to study cancer as an illness and its significance from the cultural perspective. For this reason, I use an ethnomedical approach in order to examine what kind of illness cancer is and how it has been perceived in Finnish culture over the past century. This includes study of the ethnomedical accounts of cancer from the second half of the 19<sup>th</sup> century, as well as current Internet discussions on the Forum for Finnish Cancer Patients. These sources form an extended context within which



to observe the change in popular reasoning against the background of a rapidly changing sociocultural setting.

The understanding of particular cultural settings seems essential in order to analyse cancer narratives properly. This study, based on cancer narratives, demonstrates that individual experience differs in many ways from cultural expectation. Quite often writers even attempt to deny pre-set thoughts and ideas of this kind, based on their own reasoning and experience. Naturally, it is difficult to decide which authorial voicing belongs to the external, such as culture- and language-bound ideologies, and which to the internal or personal set of cancer-related ideas. Authorial speech in cancer narratives could be interpreted as a continuous negotiation or imaginary dialogue between the personal voice and culture-bound ideas that result in authorial evaluation of the situation. To analyse and exemplify such evaluations in written texts I ask how people express their thoughts, feelings and experiences regarding cancer, and why so? The analytical units discussed in this work derive from the large text corpus representing the themes and issues that are discussed repeatedly. Thus, I suggest these are issues that cancer patients are often confronted with in everyday life; whereas narrative representation offers an insight into the important issues in cancer patients' lives. Issues that are usually covered by significant silence and therefore not discussed.

## **The historical development of popular cancer discourse**

Since the second half of the 20<sup>th</sup> century cancer has become a dominant disease in Western countries, endangering people regardless of age group, gender, race or social status. Every year almost eight million people die from cancer worldwide. Thus, a comparison with plague is not exaggerated, although, according to current medical knowledge cancer is not an endemic disease. This does not stop people from thinking cancer might be in some ways contagious. According to the evolutionary approach, there are several ecological aspects connected with the occurrences of cancer. Furthermore, new medications in use, such as antibiotics, have greatly affected human life expectancy, making cancers in old age more common than ever before. As pointed out in Chapters 5, *Popular Images of Cancer in Modern Discourse*, and 8, *Methods of Coping and Alternative or Complementary Self-Help*, cancer rates are higher because of increased awareness. Interestingly enough the

development of diagnostic techniques, which help the early detection of cancer, has also caused an increase in cancer rates.

Nevertheless, my study, based on ethnomedical records, points out that cancer has been a health problem for a long time. The previous lack of diagnostic tools meant that like doctors of the time, ordinary people also recognised cancer only when it was manually or visually detectable. As I have discussed in Chapter 4, *Cancer in Finnish Folk Medicine*, because of limited knowledge, people were unable to separate cancer from other illnesses. It was common to wait until more specific symptoms occurred before going to the doctor. For this reason, cancer patients were cared for at home using various domestic cures based on folk medical practice, such as pressing the affected area with stones or drinking liquid prepared from birch ash. I demonstrated that domestic treatments were mainly used to soothe the complications caused by incurable cancer wounds or to charm away the growths from which patients suffered. People who had gained special healing powers, used their hands to cure cancer, however people avoided direct contact with others when they were sick, which again brought out the image of cancer as contagious, an image that many still have, at least according to the cancer narratives.

During the 20<sup>th</sup> century, along with rapid changes in the medical system, people's awareness of cancer increased a great deal. This has also influenced the image of cancer in popular discourse over the past decades. From the medical point of view, cancer is a complex disease, so much so that some physicians claim every cancer should be seen as unique. Based on the cancer narratives, I would draw similar conclusions. However, it is more typical that in modern medical discourse cancer is approached as a simple cellular mutation causing changes in the body. This causes great differences in the ways in which ordinary people and professionals handle, and reason about, matters connected with cancer. From the scientific point of view there are still much that is unclear about cancer. This is a big problem as, according to culture-bound illness ideology, people falling ill need an explanation for the illness origin in order to better cope with the disease.

It is rather common in cancer narratives that people try to analyse the reasons that have led to cancer. It is important, therefore, to understand that for patients, cancer's rational explanations, given by physicians, are seen as mainly relating to the bodily experience, such as tests during follow-ups, surgery, chemical treatments, and the period of recovery; whereas the irrational meaning of cancer is often connected to human thinking and interpretation of the experienced events. This could be called a 'sense experience', which derives from the socio-historical context in which cancer is recognised as a particular 'evil

being' with supernatural qualities. As in the past, when thinking of cancer today, people perceive images of an outside intruder or stranger who enters the human body in order to harm it.

The image of illness attacking from outside is so common that it could be one reason why people find it difficult to believe in all kinds of preventative techniques, such as quitting smoking, eating healthily or taking some more exercise. In terms of avoiding cancer, people appear to reason differently: it doesn't matter what you eat or how you take care of yourself, as long as your inner protective walls hold, you will be safe.

Characteristic to any set of popular beliefs, the ideas on cancer origin found in the analysed texts are heterogeneous and contradictory. Some of these ideas are guided by language, others are culture-bound and absorbed during the socialisation process. For example, in Finnish the name for cancer is *syöpä*, the eater, perceived as a worm-like being. Therefore, from the linguistic point of view, cancer can be described as a worm-like disease that is determined to destroy the body. In contrast to Finnish, many other languages call the illness cancer, also meaning crab, which creates rather different mental connotations.

In addition to the worm aetiology provided by language, several respondents define themselves as having a cancer personality. According to their writing, they describe themselves as being weak and vulnerable, working too much, worrying too much and not taking care of themselves. Such an image of the cancer personality is pre-defined by boundaries set by our culture-bound knowledge, although the idea of the cancer personality derives from the early psychologists at the beginning of the 20<sup>th</sup> century. Although modern psychologist and psychiatrists have found no proof that personality or personal qualities affect cancer, cancer patients' narratives clearly show that if the illness is explained as the result of psychological or personal factors, it is difficult to acknowledge that only the technical modification of the body can heal the cancer. Furthermore, the lack of spiritual support from physicians is a general and often-discussed problem in cancer patients' writing.

## **Individual interpretations within linguistic and cultural frameworks**

In cancer patients' writing, which are interpretative by character as any other act of self-expression, individual experience is compared with popular images and beliefs. The study conducted here shows that, although human reasoning is open to continuous interpretation, individual interpretations are likely to correct themselves through contact with surrounding culture and linguistic ideology. Such culture-bound ideas define popular cancer discourse and its characteristic features. This means that even if people deny some of the popular ideas, they still reproduce the beliefs in their writing. For example, respondents express their ideas about the origin of cancer and deny the possibility of having a cancer personality. Such consistency in cancer discourse helps us understand and describe what is going on, particularly when dealing with a large text corpus in which numerous accounts can be said to 'interact' with each other. More importantly, such intertextual interaction brings out the idea of proactiveness hidden in popular thought, mediated as it is by various communicative means including written narratives. Thus, we have another reason to take illness narratives into serious consideration.

For a long time people were incapable of diagnosing cancer in its early stages, thus it was approached as an untreatable disease, meaning that people who contracted it were going to die sooner rather than later. This certainly explains the lethal image of cancer in popular thinking. Furthermore, even in the 1960s and early 1970s, having cancer was considered so devastating a disease that medical professionals refused to reveal the true cause of illness to their patients. Being aware of developments in the past helps us to understand why some respondents to the writing competition despise the word 'cancer' so badly that they refused to use it in everyday communication, and even avoided it in their writing. The fact that people have avoided discussing cancer in the past points out another significant aspect of the disease. Namely, as cancer has been a taboo topic, the concept itself is also considered stigmatising, which certainly affects cancer patients' reasoning when they are diagnosed with cancer. At least for a brief moment, as demonstrated in Chapter 6, *The Moment of Diagnosis and Metaphoric Transformation*, the diagnosis of cancer causes people to lose their negotiated identity and their previously established place in society.

As this study has shown, to talk or not to talk about having cancer is an important issue in cancer patients' writing. In the long text examples that I have analysed, two respondents, Ruth and Hanna, decide not to talk about their illness. Ruth explains her behaviour as follows: she cannot hurt others by talking about her illness; instead she decides that if she is mean to everyone, no one will miss her when she passes away. However, her story reveals that hiding her illness makes her feel really miserable. After sharing her big secret with those close to her, she feels a lot better. The other respondent, Hanna, again, talks about her cancer to her closest relatives, and becomes angry when one relative shares this with the rest of the world. According to her writing, Hanna never tells her work colleagues about her illness. She is afraid that one of them might confront her with inconvenient questions about her health in unexpected situations. Both stories reproduce the idea that being diagnosed with cancer leads to death. Furthermore, Ruth and Hanna's writing, like many other narratives analysed in this work, clearly demonstrate that discussing cancer in public is problematic for many reasons.

The analysis of the cancer narratives highlights the significant silence in culture-bound cancer discourse, which is connected to cancer patients' fears of being labelled or judged by society. By throwing light on areas of the past, I have established a context that can help understanding of why it is difficult to talk about cancer, and of the most significant myths surrounding this illness among cancer patients. Analysing the popular images of cancer in the cultural context has also given an answer to my second research question: why do people write about their illness? Based on the cancer narratives, various culture-bound restrictions surrounding the subject become apparent, which explains the need for written self-expression among cancer patients. The opportunity to write about cancer and share personal thoughts, feelings and experiences has been accepted as an excellent way of expressing ideas suppressed in everyday communication.

## **Representations or reconstructions of lived experiences**

The interpretation of written narrative is linked to popular ideas, lived experiences and their representations and reconstructions in written narratives. The materials used here show that one of the most common culture-bound ideas about cancer is cancer's direct connection to death in human reasoning. This connection comes from the past and forces people to avoid the subject in everyday discussions. Talking about life-threatening illnesses

and death may cause uneasiness between communicative parties, which means that cancer patients must find other ways to express themselves. Written self-expression, no doubt, offers a good possibility to share one's suppressed thoughts without being judged or labelled by others. This also explains the great interest towards the archival request regarding the collecting of cancer experiences. According to the co-letters, the archive's request offered an additional path by which to express ideas that run against the culturally or socially agreed ideologies.

In their writing, rather unexpectedly, numerous participants had chosen to bring out the positive sides that the experience of having cancer had brought. In addition, the lethal image of cancer is challenged by examples based on individual experience, which is also understandable considering the number of patients who are eventually cured. People claim that having cancer helped them understand how human life unfolds, and that even if illness occurs other things take place as well: people fall in love, graduate school, babies are born, new hobbies discovered or old ones regained, etc. Thus, the image of cancer may have relative significance in human life, particularly if compared to other threats that put people's lives in danger: "*Jo ekana päivänä ma keksin hyvän lohdutuslauseen: On sentään parempi kuulla, että sulla on syöpä kuin että sulla on AIDS*", "Already on the first day I came up with a good comfort slogan: 'It is better to hear that you have cancer than AIDS.'" (087)

Respondents also seem to share the idea that life is a road trip that doesn't last forever (*elämän mittainen matka*). This road-trip has a certain length in the human mind based on cultural understanding and personal expectation. When it finishes before the expected time, people are not able to accept it without crises. However, when the crisis is over many patients find that the length of life is not so important. More important is that they have lived a satisfactory life that provides precious experiences – both good and bad (313).

Writing is a good tool with which to express, analyse and interpret complicated personal situations, and therefore participating in the writing competition has a great therapeutic importance for respondents. One important task of the cancer narrative is to describe the individual's cancer experience in order to remember, analyse and communicate the lived experience. The reconstructions presented in the narratives are dependent on the illness course as well as the narrative tendencies and respondents' primary purposes for writing. This means that despite constantly recurring themes, cancer narratives are by no means identical. In my opinion, it is not beneficial to classify these texts by certain narrative tendencies, or by the myths they provide. To understand and appreciate the uniqueness of

the stories seems far more useful. This of course makes the interpretation of written narratives particularly challenging.

## **Practical structuralism and evocative milieux as factors impacting on the archival request**

The writing process is complicated because it forces authors to choose between relevant and irrelevant themes. In general, illness narratives follow the culturally agreed structure of the pathological drama or illness course. Therefore, I have used practical or descriptive structuralism to describe how the stories are composed, in order to highlight their responsive character. Normally the cancer narrative describes the events that occur when a person falls ill. Some narratives also include descriptions of pre-symptomatic conditions and the post-recovery period, depending on the course of the illness. However, as the cancer narratives under study have been collected by archival request, the analysed narratives, unlike book-length pathographies, have a mainly ethnographic value. The lack of literary features does not diminish the cancer narrative's significance as research material. Respondents have written down and interpreted their illness experiences according to the open-ended questions posed by the organisers of the archival request. Thus the stories gain an evaluative character. Despite the structural similarity, some writing contains more evaluation than others, depending on the respondent's written self-expression skills and their authorial intentions and selected tendencies. Thus, the collected writing allows study of the cancer experience on the individual, cultural and societal levels using the narrative approach, whereas the written form gives to cancer narratives a certain autonomic value when they are studied.

The autonomy of written texts allows the study of the external and internal meanings implied by authors within a thematically united text. However, when talking about cancer narratives, it is difficult to decide which of the authorial voicings belongs to the external, such as culture- and language-bound ideologies, and which to the internal or personal set of cancer-related ideas. Naturally, the respondents choose the intentions of their narratives, as well as setting the timeline necessary to make themselves understandable. In their stories writers evaluate the period before and after the diagnosis, and also examine their feelings in different temporally and spatially defined situations. Thus, a great part of the narrating or writing process is connected with imaginary dialogue between man and self.

Nevertheless, when dealing with cancer patients' writing we cannot reject the idea that the stories also have a communicative value, representing an ongoing dialogue between other communicative parties and the particular evocative milieux involved. Thus, the descriptions of individual experiences are drawn upon 'responsive' understanding and reception, which above all is defined by the writing competition dealing with cancer patients' experiences; meaning that the author's personal voice is controlled by culture-bound expectations as well as the expectations of the organisers of the archival request.

The structural analysis of cancer narratives points out that hospital events gain a dominant role in cancer narratives. The stories reveal that the time spent in hospital is important because it leads to certain solutions in the cancer battle, but also because it is a process provided and controlled by society. For patients, the time spent in hospital represents a period in their lives when attachment to the self becomes loose because they are handled as people with limited rights.

Although people are convinced that a large part of the healing process is dependent on their individual decision making and self-help, somehow the events that take place in healthcare centres and cancer clinics appear to dominate the cancer narratives. This demonstrates that people have certain expectations from their writing. As the writing competition was organised in collaboration with cancer patients' organisations, the writers are careful about sharing the experiences they gained in hospital. I suggest they use their writing as a channel to discuss various aspects connected to doctors, hospital personnel, the treatments given as well as the socially supported medical system in general. In hospital the respondents were expected to be patient patients, and similarly, in their writing they are expected to share their minds: talk about their experiences in the hospital as well as psychological advice and support. I suggest that this is the main reason why cancer narratives contain lots of criticism of modern medicine and the ways people are handled in healthcare institutions. I would like to point out that this kind of criticism does indicate that there would be no gratitude towards the help provided. Rather the opposite, people who have received good care and understanding mention it in their writing, however, misunderstandings and lack of attention as individuals make people write longer stories as the archival request has given them an excellent opportunity to do so.



## **Patients' feelings and suppressed ideas revealed in metaphors and dreams**

The close examination of cancer narratives highlighted three important issues that should be noted when dealing with materials collected via archival request: Firstly, narratives are interpretations of experience, which means that the writing, although containing truthful events, follow certain narrative tendencies and authorial intentions that make the events described different from actual life events. The representations or reconstructions of illness experiences include respondents' individual negotiations and interpretations that evaluate the meaning of cancer in their lives and therefore the events described must be pre-selected in order to become meaningful within a narrative.

Secondly, cancer narratives are thematic and, in general, follow the culturally agreed structure of the pathological drama or illness course. The ways the stories are structured or put together are dependent on the writers' competence and skills of self-expression; however, the narratives also have a responsive character in order to meet the expectations of the organisers of the writing competition. The writers' intentions are to be understood, which means their stories must have certain frameworks, which to a certain extent are in accordance with culture-bound ideas and socioculturally defined cancer discourse.

Thirdly, interpreting the written narratives of the writing competition as wholes is a complicated task because of their idiosyncratic nature. Nevertheless, the large text corpus they provide creates an excellent context within which comparison can highlight similarities and differences, and to identify units that are useful for analytical study. In my opinion such intertextual comparison based on a large text corpus allows the creation of sufficient arguments, as well as results, and with those hopefully generates ideas for further discussion.

Interpreting written narratives as wholes is a complicated task because of their idiosyncratic nature. This is connected to the fact that every time cancer occurs it is different, as are the narrative tendencies, intentions, and the self-expression skills of respondents. As analysing the whole story is a complicated task, the smaller narrative parts, both descriptive and narrative-like, gain more significance. This leads to the situation in which the researcher's interests take over the writer's interests. For the writer, the various episodes are just building blocks to put together the whole in order to construct a narrative. For the researcher, the possibility to compare different narratives and analyse the

primary units within larger contexts, such as the intertextual universe constructed by the large text corpus, reveals the particular qualities of written narratives. Thus, not only the described events and experiences, but also the inner feelings and thoughts of respondents become significant objects of observation. Particularly because writing is an opportunity for self-expression, which helps to clear the mind and make complicated issues understandable. And, as cancer narratives reveal, people choose to write instead of speaking because, as cancer patients, they often are reinforcing the fact that cancer is a culturally stigmatised issue that should not be discussed in public.

When dealing with cancer narratives I have asked myself how people write about their thoughts, feelings and experiences. This was a question that made me study what I have called spontaneous accounts in cancer patients' narratives: firstly, metaphors relating to falling ill; and secondly, dreams connected with the process of being ill. Apparently, in their writing, people go through feelings and experiences gained in the past. Although their stories are reconstructions of past events, the multiple paths of self-expression present in written narratives have needed careful examination to understand their significance.

In order to illustrate the complexities present in understanding the role of metaphor, I have examined how metaphors work and what they do in particular situations. For an in-depth analysis I selected the moment of cancer diagnosis, which may be interpreted as the most crucial in the cancer experience as for many cancer patients it causes inner chaos and loss of self. This is the moment when people lose their negotiated identity and their previously established place within society. According to culture-bound reasoning, the moment of diagnosis can be seen as a moment of transformation from an ordinary person into a cancer patient. I have noted that to describe the transformation into patient the associated inner chaos personal emotions become verbalised and expressed using metaphors. I suggest that these pictures words in the texts aim to recall embodied experience and the connection these have to reality in order to make individual feelings perceivable to others. I came to the following conclusions on this subject: firstly, metaphors function as a culture-bound key with which to make comprehensible individual emotions; secondly, metaphor, as a primary unit, contains the freedom to choose a suitable word order, as well as the requisite amount of emotion in order to mediate in pictures words the situation in which cancer sufferers find themselves; and thirdly, the poetic freedom present within metaphor is used when respondents construct their particular "work in miniature" and make it a part of their thematic writing.

Like metaphors, dreams and dream narratives may be interpreted as spontaneous accounts in cancer narratives. Omens, nightmares, or ameliorating dream imagery have individual value, although considering the whole text corpus dreams form a particular milieu in cancer narratives. In my work I suggest that through dreams the respondents deliver intimate situations that allow the discussion of themes that would be considered marginal, according to linguistic ideology or culturally defined discourse in different speech situations. As with everyday communication, the whole process of communicating cancer-related issues is understood as marginal, and sometimes even covered by significant silence. Therefore, the function and meaning of dream accounts represented in the cancer patients' narratives becomes particularly significant. I point out that dreams and dream-like imagery are interpreted as events that gain meaning from everyday life, and particularly in connection with the illness process. There are many taboos related to discussing cancer and even subjects relating to it, whereas talking about dreams has been interpreted as an entertainment among most people. Apparently, this does not create uneasiness in other communicative parties, and people who go through emotionally difficult times may employ their significant dream experience repeatedly to talk about their fears and concerns. The fact that dreams become an important part of the cancer narrative is certainly because of their significance in everyday communication. Dream narratives allow patients to share their concerns and thus may help them through emotionally complicated periods.

The patients' narratives, composed of various structural segments, are reconstructions of self-negotiation and individual decision making during illness. In addition, such texts describe feelings that appear insignificant to modern medicine, overwhelmed as it is by medical technologies and concentrating only on dysfunctional tissue within 'diseased' bodies. In this way, cancer patients' writing gives access to the human side of cancer discourse, which combines medical knowledge with popular knowledge of cancer. However, because of their narrative value, representations of cancer experience can be like fairy tales, where the evil one is destroyed and the heroes and heroines continue living happily ever after. We, as receivers, are likely to believe this, however, we really do not know if this image of the happy survivor given in the narratives is entirely true, partly true, or is it just vivid imagination or wishful thinking. This characteristic feature of cancer narratives also leads to the suggestion that beyond the available, accessible, materials, something else may lie that remains undetected and undetectable.

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Ref. Nr	Pages	Sex	Date of birth	Place of residence	Cancer experience/age of falling ill	Cancer type
001	1-10	F	1978	2	grandfather (37)	Stomach Cancer
002	11-17	F	1921	1	mother	Pancreatic/Stomach Cancer
003	18-24	F	1937	1	self	Skin Cancer
004	25-27	F	1919	3	self (69)	Lung Cancer
005	28-31	F	1935	1	husband	Leukaemia?
006	32-36	F	1939	4	self (45)	Thyroid Cancer
007	37-40	F	1923	6	self (46)	Breast Cancer
008	41-59	M	1896	3	self	Skin Cancer?
009	60-81	F	1931	2	self (54)	Breast Cancer
010	82-85	F	1927	6	self (44)	Gyn. Cancer
011	86-101	F	?	9	son (5)	Leukaemia
012	102-106	F	1934	1	self (50)	Breast Cancer
013	107-118	F	?	9	husband (18?)	Thyroid Cancer
014	119-124	F	1916	9	husband (72)	Gullet Cancer
015	125-128	F	?	9	self (45)	Gyn. Cancer
016	129-131	F	1947	7	self	Breast Cancer
017	132-134	F	1926	1	self (65)	Gyn. Cancer
018	135-136	F	1914	6	self (62)	Breast Cancer
019	137-142	F	1925	0	self (65)	Thyroid Cancer
020	143-151	F	1945	6	self (47)	Leukaemia
021	152-154	F	?	?	self	Gyn. Cancer/Breast Cancer
022	155-159	F	1950	2	family	Various
023	160-162	F	1923	1	self	Leukaemia?
024	163-183	F	?	0	self (70)	Gyn. Cancer
025	184-188	F	?	0	self	Breast Cancer
026	189-197	F	1939	6	self	Lymphoma
027	198-199	F	?	0	someone else	?
028	200-208	F	1924	z (Expatriate)	mother (56) 1963	Stomach Cancer
029	209-211	F	1935	6	self (58)	Breast Cancer
030	212-215	F	1930	0	self (47) 1977	Gyn. Cancer
031	216-236	F	1929	6	self (62) 1992	Breast Cancer
032	237-240	F	1925	0	self (47) 1972	Gyn. Cancer
033	241-246	F	1940	7	self (47) 1987?	Gyn. Cancer
034	247-248	F	1924	7	self (70) 1993	Gyn. Cancer
035	249-252	F	1922	7	self (55) 1977	Pancreatic/Stomach Cancer
036	253-256	F	1962	7	mother (55) 1977	Pancreatic/Stomach Cancer
037	257-257	M	1924	8	self (70) 1993	Prostate Cancer
038	258-273	F	1947	1	self (46) 1993	Skin Cancer
039	274-275	M	1953	3	self (37) 1990	Pancreatic/Stomach Cancer
040	276-278	F	1944	1	husband (48)	Colon Cancer
041	279-280	F	?	2	daughter (1y 6m) 1990	?
042	281-282	F	1934	1	self	Breast Cancer
043	283-290	F	?	6	husband (67) 1994	Stomach Cancer
044	291-296	F	1922	0	self (62) 1984	Breast Cancer
045	297-298	F	1977	6	mother 1977	Breast Cancer
046	299-315	F	1958	0	self ( 34) 1992	Breast Cancer
047	316-325	F	1915	5	son (50) 1992	Lymphoma
048	326-334	F	1943	3	self (33) 1976	Breast Cancer
049	335-343	F	?	0	mother (83)	Gallbladder Cancer

050	344-348	F	1941	0	self (49) 1991	Liposarcoma
051	349-356	F	1959	4	mother (35) 1969, father 1986	Leukaemia/Lung Cancer
052	357-361	F	1938	4	self (49) 1987	Intestinal/Gyn. Cancer/Gyn. Cancer
053	362-364	F	1929	7	husband 1984, self (55) 1985	Brain Cancer/Pancreatic Cancer, Breast Cancer
054	365-381	M	1945	0	wife 1987/89	Breast Cancer/Gyn. Cancer/Gyn. Cancer
055	382-383	F	1911	2	self (79) 1990	Urinary/Bladder Cancer
056	384-395	F	?	1	self 1989	Skin Cancer
057	396-410	F	1931	0	daughter (14) 1990	Leukaemia
058	411-461	M	1914	8	self (69) 1983	Throat Cancer
059	462-488	M	1929	6	wife (69) 1994	Stomach Cancer
060	489-511	F	1921	0	self (65) 1986	Colon Cancer
061	512-544	F	?	6	mother 1984	Breast Cancer
062	545-551	F	?	2	self 1990	Breast Cancer
063	552-554	F	1942	6	father (apx. 1950)	Stomach Cancer
064	555-560	F	1943	0	mother (79) 1992	Pancreatic Cancer
065	561-564	F	1950	8	self (42) 1992	Lymphoma
066	565-572	F	1937	0	self (50) 1983/1987	Breast Cancer
067	573-581	F	1963	3	self (25) 1988	Skin Cancer
068	582-586	F	1932	3	self	Breast Cancer
069	587-589	F	1939	8	self (58) 1991	Breast Cancer
070	590-591	F	1921	0	husband	Urinary/Bladder Cancer
071	592-592	F	?	0	sister	?
072	593-595	F	?	7	self (50+)	Kidney Cancer
073	596-599	F	?	1	self/husband/mother	?
074	600-603	F	1934?	2	sister (60)	?
075	604-607	F	?	2	self (36) 1960	Gyn. Cancer
076	608-610	M	1925	4	self (55) 1980	Stomach Cancer
077	611-616	F	?	3	self (?) 1970	Thyroid Cancer
078	617-635	F	?	1	self	?
079	636-640	F	1938	3	self (48) 1986	Colon Cancer
080	641-644	F	1939	6	sister	?
081	645-653	F	1934	0	self (58) 1992	Gyn. Cancer
082	654-658	F	1962	9	self (29) 1991	Breast Cancer/Lymphoma
083	659-667	F	?	9	son (1y 10m) 1991	Kidney Cancer
084	668-672	F	1924	0	father 1969	Cheek Cancer (?)
085	673-676	F	1924	1	self (58) 1982	Gyn. Cancer
086	677-689	F	1973	7	mother 1986	Backbone Cancer
087	690-711	F	?	0	sister (29) 1991/1993	Breast Cancer
088	712-727	F	1953	6	self (33) 1986	Spinal Cancer
089	728-733	F	1953	6	self (39) 1992	Breast Cancer
090	734-740	F	1948	9	self	Kidney Cancer
091	741-746	F	1953	9	self (34) 1988	Breast Cancer
092	747-747	F	1952	1	self (50) 1992	Leukaemia
093	748-756	F	1926	1	self (67) 1993	Breast Cancer
094	757-761	F	1918	8	self (51) 1969	Breast Cancer
095	762-792	F	1926	9	self (58) 1984	Throat Cancer
096	793-799	F	1941	1	grandchild (1y 10m)	?
097	800-802	F	1919	0	self (apx. 45)	Colon Cancer
098	803-815	F	?	9	self 1980	Breast Cancer
099	816-822	M	?	9	wife 1994	Gyn. Cancer
100	823-849	M	1929	0	self (60) 1989	Lymphoma
101	850-862	M	1926	4	self (65) 1992	Intestinal Cancer
102	863-877	F	?	0	self 1991	Gyn. Cancer



103	878-883	F	1935	0	self (26) 1961	Skin Cancer
104	884-887	F	?	3	husband (48) 1991	Stomach Cancer
105	888-896	F	1913	1	cousin 1953	?
106	897-944	F	1951	0	child (3) 1990	Kidney Cancer
107	945-949	F	1924	1	self (66) 1990	Breast Cancer
108	950-951	F	1927	9	self (59) 1986	Breast Cancer
109	952-958	F	1941	8	self (46) 1987	Breast Cancer
110	959-979	F	1916	0	father (59) 1945, sister (68) 1983, boss (82) 1985	Prostate Cancer, Lung Cancer
111	980-985	F	1931	8	self (54) 1985	Gyn. Cancer
112	986-993	F	?	5	self 1972	Breast Cancer
113	994-1 001	F	1948	0	self	Breast Cancer
114	1 002-1 008	F	1931?	5	self (33) 1964	Breast Cancer
115	1 009-1 021	F	1954	0	sister 1990	Lymphoma
116	1 022-1 023	F	1947	1	daughter (16) 1982	?
117	1 024-1 024	M	1923?	1	self (60) 1983	Kidney Cancer
118	1 025-1 026	F	1916	1	self (62) 1978	Gyn. Cancer
119	1 027-1 032	F	1918	z (Expatriate)	mother (65) 1964	Stomach Cancer
120	1 033-1 037	F	1954	3	self (40) 1994	Breast Cancer
121	1 038-1 045	F	1947	7	self 1992	Breast Cancer
122	1 046-1 051	F	?	2	self	?
123	1 052-1 055	F	?	0	father 1994	Stomach Cancer
124	1 056-1 059	F	1919	1	self (69) 1988	Lymphoma
125	1 060-1 061	F	?	0	self (56) 1992	Breast Cancer
126	1 062-1 065	F	1955	7	self (19) 1974	Lymphoma
127	1 066-1 083	F	1944	4	father (80?) 1992	Stomach Cancer
128	1 084-1 089	M	1957	0	sister (35) 1993	Brain Cancer
129	1 090-1 093	M	1940	4	self (35) 1975, wife 1977	Lung Cancer, Brain Cancer
130	1 094-1 097	F	?	7	self 1992	Breast Cancer, Gyn. Cancer
131	1 098-1 104	F	?	7	self 1989	Breast Cancer
132	1 105-1 106	F	?	3	self 1980	Breast Cancer
133	1 107-1 114	F	1931	4	self (23) 1955	Breast Cancer
134	1 115-1 118	F	1923	2	self (70) 1993	Breast Cancer
135	1 119-1 125	F	1944	7	self (50) 1994	Lymphoma
136	1 126-1 134	F	?	7	self (?) 1994	Skin Cancer (Carcinoma Basocellulare)
137	1 135-1 140	F	1947	1	self (45) 1992	Breast Cancer (Mamma Carcinoma)
138	1 141-1 145	F	1909	5	self (37) 1946	Gyn. Cancer
139	1 146-1 155	F/M	1970	9	brother (16) 1989	Leukaemia
140	1 156-1 163	F	?	0	self	Breast Cancer
141	1 164-1 170	F	1943	2	self	Breast Cancer
142	1 171-1 174	F	1942	9	self (44) 1986	Breast Cancer
143	1 175-1 208	F	1919	0	husband (?) 1994	?
144	1 209-1 214	F	1922	4	self (62) 1984	Skin Cancer
145	1 215-1 218	F	1941	0	self (52) 1993	Lymphoma
146	1 219-1 243	F	1925	8	self (60) 1985	Gyn. Cancer
147	1 244-1 256	F	1919	0	self (57) 1976	Breast Cancer
148	1 257-1 261	F	1941	1	self	Breast Cancer
149	1 262-1 267	F	1925	0	self (59) 1984	Mouth cancer
150	1 268-1 274	F	1925	1	self (55) 1990	Breast Cancer
151	1 275-1 278	M	1954	3	self (40) 1994	Trachea Cancer
152	1 279-1 281	F	1920	3	self (67) 1987	(no cancer)
153	1 282-1 288	F	1922	6	self (49) 1971	Gyn. Cancer
154	1 289-1 294	F	?	3	self 1970	Eye, Liver cancer, Gyn. Cancer, Lymphoma
155	1 295-1 300	F	1919	5	self	Colon Cancer

156	1 301-1 305	F	?	0	sister 1979	Breast Cancer/Gyn. Cancer
157	1 306-1 441	F	1938	9	husband (51) 1989	Prostate Cancer
158	1 442-1 449	F	1944	7	self (50) 1994	Breast Cancer
159	1 450-1 463	F	1964	5	father 1987	Brain Cancer
160	1 464-1 471	M	1916	6	self (74) 1990	Colon Cancer
161	1 472-1 472	F	1931	6	self	Breast Cancer
162	1 473-1 481	F	1931	2	mother (70) 1974	Gullet/Stomach
163	1 482-1 485	F	?	0	husband 1992	Lung Cancer (Mesotelioma)
164	1 486-1 491	F	1919	1	self (30) 1951	Gyn. Cancer
165	1 492-1 505	F	1945	9	self (47) 1992	Thyroid Cancer
166	1 506-1 507	F	?	9	mother 1981	Gyn. Cancer
167	1 508-1 514	F	1933	3	self (35) 1968/husband 1986	Gyn. Cancer
168	1 515-1 518	F	?	5	mother 1989	?
169	1 519-1 524	F	1936	2	self	Breast Cancer
170	1 525-1 533	F	1941	3	son (11) 1991	Brain Cancer
171	1 534-1 536	F	1957	4	father	Colon Cancer
172	1 537-1 539	F	?	6	self 1982	Small Intestine, Urinary/Bladder Cancer
173	1 540-1 552	M	1924	0	self (66) 1990	Prostate Cancer
174	1 553-1 554	F	1939	3	self (48) 1987	Breast Cancer
175	1 555-1 559	F	1921	4	self (47) 1986	Breast Cancer
176	1 560-1 565	F	?	3	self 1978	Breast Cancer
177	1 566-1 575	F	1935	5	self (52)	Breast Cancer
178	1 576-1 582	M	1945	0	mother (73) 1985	Skin Cancer
179	1 583-1 605	M	?	9	daughter (5) 1973	Leukaemia
180	1 606-1 611	F	1968	1	mother	Breast Cancer
181	1 612-1 613	F	1952	6	father	Lung Cancer
182	1 614-1 615	F	1910	2	self (73) 1983, 1993	Breast Cancer
183	1 616-1 625	M	1946	4	self (46) 1992	Lymphoma
184	1 626-1 630	F	?	6	self	Breast Cancer
185	1 631-1 637	F	1925	4	father 1977, self (54) 1986	Throat Cancer, Breast Cancer
186	1 638-1 653	F	?	4	friend 1972, 1988, 1993 (48)	Breast Cancer/Lung Cancer
187	1 654-1 660	F	1926	8	husband 1983/1992	Mouth Cancer/Lung Cancer
188	1 661-1 675	F	1940	5	self (52) 1990	Breast Cancer
189	1 676-1 684	F	1964	8	child (11 months) 1993	Leukaemia
190	1 685-1 693	F	1922	1	self (63) 1985	?
191	1 694-1 696	M	1925	7	self (52) 1983	Throat Cancer
192	1 697-1 704	F	1944	6	self (50) 1994	Myeloma
193	1 705-1 712	F	1946	9	self (42) 1988	Breast Cancer
194	1 713-1 716	F	1935	3	self (48) 1974	Breast Cancer
195	1 717-1 724	F	1935	2	self (45) 1980	Breast Cancer
196	1 725-1 730	F	1942	2	self (43) 1985	Lung Cancer
197	1 731-1 732	F	1927	4	mother (?) 1939/42	Stomach Cancer
198	1 733-1 735	M	?	1	self 1960	Skin Cancer
199	1 736-1 739	F	1929	6	self (69) 1994	Breast Cancer
200	1 740-1 744	F	1936	6	1961, 1970, 1981, 1989, 1991, 1993	Gyn. Cancer, etc.
201	1 745-1 758	F	1948	0	self (41) 1989	Lymphoma
202	1 759-1 773	F	?	0	self 1985	Breast Cancer
203	1 774-1 779	F	1950	9	self (34) 1984/85	Colon Cancer
204	1 780-1 788	F	1930	0	self (61) 1991	Breast Cancer
205	1 789-1 808	F	1924	0	father, self (32) 1956	Lung Cancer, Breast Cancer
206	1 809-1 817	F	1941	2	self (50) 1991	Breast Cancer
207	1 818-1 819	F	1931	5	friend (64) 1993	Lung Cancer
208	1 820-1 822	M	1955	0	sister 1986	Breast Cancer

209	1 823-1 825	F	1921	0	self (27) 1948	Kidney Cancer
210	1 826-1 831	F	1923	0	self (57) 1980	Thyroid Cancer
211	1 832-1 842	F	1953	2	self (40) 1994	Breast Cancer
212	1 843-1 852	F	1915	8	self (37) 1952, 1984, 1994	Breast Cancer, Lymphoma, Breast Cancer, Bone Cancer
213	1 853-1 856	F	1918	6	self (42) 1960	Breast Cancer
214	1 857-1 865	F	1921	3	self (35) 1957	Gyn. Cancer
215	1 866-1 880	F	1952	3	self	Breast Cancer
216	1 881-1 884	F	1930	3	self (45) 1975	Gyn. Cancer
217	1 885-1 891	F	1930	0	self (59) 1989	Breast Cancer
218	1 892-1 894	F	1947	2	father 1988	Pancreatic Cancer
219	1 895-1 903	F	?	8	father (56) 1957/58, husband (57) 1976/83	Pancreatic Cancer, Skin Cancer
220	1 904-1 923	M	1922	0	wife 1984, self (62) 1984, brother (69) 1989, friend 1989, daughter 1990, friend 1990	Breast Cancer, Prostate Cancer/Kidney Cancer, Lung Cancer, Pancreatic Cancer, Breast Cancer, Liver Cancer
221	1 924-1 938	F	1952	1	daughter (12) 1990	Bone Cancer (Osteosarcoma)
222	1 939-1 949	F	1940	0	sister (51) 1986	Lung Cancer
223	1 950-1 967	F	1960	4	self (27) 1988	Lymphoma, Leukaemia
224	1 968-1 979	M	1926	7	self (62) 1988, 1892	Kidney Cancer, Lung Cancer
225	1 980-2 010	F	1955	5	self (38) 1993	Breast Cancer
226	2 011-2 015	F	?	8	self (?) 1972	Liver Cancer
227	2 016-2 020	F	1948	2	self (45) 1993	Breast Cancer
228	2 021-2 030	F	1937	4	self (23) 1961	Reymond's Syndrome
229	2 031-2 035	F	1937	4	self (47) 1984	Breast Cancer
230	2 036-2 044	F	?	0	self 1985	Gyn. Cancer
231	2 045-2 055	F	?	1	self 1993	Breast Cancer
232	2 056-2 077	M	1929	0	self (63) 1992	Urinary/Bladder Cancer
233	2 078-2 099	M	?	2	self	Lymphoma
234	2 100-2 107	F	1971	3	father 1991	Lung Cancer
235	2 108-2 114	M	1944	9	father 1988, mother 1988/89	Lung Cancer/Lung Cancer
236	2 115-2 116	M	1922	6	self (45) 1967	Lip Cancer, Lung Cancer
237	2 117-2 122	F	1922	0	self (44) 1966, 1993	Gyn. Cancer, Colon Cancer
238	2 123-2 124	M	1974	5	self (16) 1994	Leukaemia
239	2 125-2 129	F	1937	1	self (55) 1992	Breast Cancer
240	2 130-2 140	F	1931	7	self	Breast Cancer
241	2 141-2 149	F	1954	9	child (4) 1987	Lymphoma (Lymphoma Malignum)
242	2 150-2 157	M	1943	2	self (50) 1993	Gallbladder Cancer
243	2 158-2 163	F	1962	0	father 1993	Lung Cancer
244	2 164-2 177	F	1954	3	self (34) 1989	Breast Cancer
245	2 178-2 186	F	?	8	self 1992	Breast Cancer
246	2 187-2 215	M	1913	7	wife 1953, 1981 self 1976	Breast Cancer, Kidney Cancer/Skin Cancer
247	2 216-2 218	F	1925	8	self (61) 1968, 1984	Breast Cancer
248	2 219-2 228	F	1921	6	self (69) 1990	Tongue Cancer
249	2 229-2 232	F	1920	3	self	?
250	2 233-2 242	F	1945	5	self (39) 1984	Breast Cancer
251	2 243-2 252	F	1915	8	self (33) 1948	Breast Cancer
252	2 253-2 262	F	?	7	self 1992, father 1983, son (4) 1993	Breast Cancer
253	2 263-2 264	F	1948	8	father 1994	?
254	2 265-2 265	F	?	2	self 1988	Lymphoma
255	2 266-2 273	F	1942	4	husband (56)	Kidney Cancer
256	2 274-2 323	F	1941	2	self (49) 1990	Colon Cancer
257	2 324-2 335	F	1957	0	self (33) 1991	Thyroid Cancer
258	2 336-2 340	F	1919	0	self (45) 1964	Colon Cancer

259	2 341-2 357	F	1917	0	self (50) 1967, 1971, 1985, 1988	Gyn. Cancer, Kidney Cancer, Breast Cancer
260	2 358-2 366	M	1940	3	self (20) 1960	?
261	2 367-2 372	F	1936	3	self	Breast Cancer
262	2 373-2 383	F	1921	4	self (41) 1963	?
263	2 384-2 391	F	1937	2	self	Breast Cancer
264	2 392-2 406	F	1946	7	self (43) 1989	Breast Cancer
265	2 407-2 415	F	1941	3	self (50) 1991	Breast Cancer
266	2 416-2 418	F	1948	3	self (45) 1993	Breast Cancer
267	2 419-2 427	F	1923	6	self (63) 1986	Stomach Cancer
268	2 428-2 468	F	1938	6	self (50) 1988	Gyn. Cancer
269	2 469-2 474	F	1942	4	son (3) 1974	Leukaemia
270	2 475-2 477	F	1920	3	self (67) 1987, 1993	Breast Cancer
271	2 478-2 485	F	1944	2	self (42) 1988	Breast Cancer
272	2 486-2 496	M	1949	2	father 1969, mother 1987, 1989	Intestinal/Gullet Cancer, Liver Cancer
273	2 497-2 505	F	?	0	daughter	Leukaemia
274	2 506-2 506	M	1970	3	self (24) 1994	Lymphoma
275	2 507-2 516	F	1914	0	self	Breast Cancer, Lung Cancer, etc.
276	2 517-2 520	F	1931	5	self	Colon Cancer
277	2 521-2 524	F	?	8	self 1991	Breast Cancer
278	2 525-2 530	M	1940	2	self	Lung Cancer
279	2 531-2 537	F	?	2	husband (67) 1991	Lung Cancer
280	2 538-2 539	F	?	1	sister 1982	Gyn. Cancer
281	2 540-2 541	F	?	1	mother (76) 1993	Gyn. Cancer
282	2 542-2 553	F	1941	0	self (38) 1983	Breast Cancer
283	2 554-2 555	M	?	0	self	?
284	2 556-2 566	F	1918	0	self (72) 1990	Kidney Cancer
285	2 567-2 610	F	1929	0	husband (59) 1988, self	Lymphoma/Breast Cancer
286	2 611-2 631	F	1923	0	self (41) 1964, 1970	Thyroid Cancer
287	2 632-2 636	F	1972	1	self (5) 1978	Leukaemia
288	2 637-2 640	F	1959	0	mother-in-law, mother	Colon Cancer, Liver Cancer
289	2 641-2 652	M	1943	1	self (50) ?1993	Leukaemia
290	2 653-2 659	F	1947	3	self (36) 1983	Breast Cancer
291	2 660-2 665	F	1936	0	self (50) 1986	Breast Cancer
292	2 666-2 667	F	1950	2	self (44) 1994	Breast Cancer
293	2 668-2 669	F	?	2	self 1992	Breast Cancer
294	2 670-2 672	F	?	8	self 1989	Breast Cancer
295	2 673-2 678	F	1938	5	self 1977	Breast Cancer
296	2 679-2 690	F	1921	6	daughter (9) 1955, father (88)	Leukaemia
297	2 691-2 698	F	1944	2	self (49) 1994	Colon Cancer
298	2 699-2 705	F	1952	6	self (37) 1989	Thyroid Cancer
299	2 706-2 711	F	1935	9	self (52) 1987, husband 1969/71	Breast Cancer/Lung Cancer
300	2 712-2 716	F	1971	0	father 1985	Pancreatic Cancer
301	2 717-2 727	F	1941	1	self (51) 1992	Breast Cancer
302	2 728-2 730	F	1947	1	self (45) 1992	Lung Cancer
303	2 731-2 754	F	1924	7	self (32) 1956, 1982	Lymphoma, Gyn. Cancer
304	2 755-2 757	F	1931	0	self (46) 1978	Breast Cancer
305	2 758-2 760	F	?	2	father (68)	Prostate Cancer
306	2 761-2 814	F	1930	0	self (63) 1993	Breast Cancer
307	2 815-2 819	F	1934	6	self	Breast Cancer
308	2 820-2 824	F	1975	8	grandmother (?) 1994	Gyn. Cancer
309	2 825-2 830	F	?	8	self (?) 1988	Gyn. Cancer
310	2 831-2 833	F	1909	1	husband 1981/83	?
311	2 834-2 836	F	1934	2	self (54) 1988	Lymphoma

312	2 837-2 843	F	1973	6	father (48)	Lymphoma
313	2 844-2 850	F	?	3	self 1990	Gyn. Cancer
314	2 851-2 895	F	1958	9	father (42?) 1966, self (35) 1993	Colon Cancer
315	2 896-2 899	F	1948	8	self (43) 1991	Breast Cancer
316	2 900-2 915	F	1921	3	self (70) 1991	Breast Cancer
317	2 916-2 925	F	1930	5	self (60) 1990	Lymphoma
318	2 926-2 938	F	1950	3	self (34) 1984	Breast Cancer
319	2 939-2 943	F	1930	5	self (57) 1987	Breast Cancer
320	2 944-2 946	F	?	0	self 1975	Skin Cancer
321	2 947-2 952	F	1928	8	mother, self	Breast Cancer
322	2 953-2 955	M	?	2	self 1988	Stomach Cancer
323	2 956-2 965	F	1936	0	husband 1987	Lung Cancer
324	2 966-2 978	F	1954	2	self 1980s	Gyn. Cancer
325	2 979-2 988	F	1961	9	self (31) 1992	Thyroid Cancer
326	2 989-2 993	F	1929	0	husband (62) 1993	Urinary/Bladder Cancer
327	2 994-3 000	F	1942	2	self (49) 1991	Breast Cancer
328	3 001-3 013	F	?	9	self 1979	Breast Cancer
329	3 014-3 035	F	1935	9	husband 1992	?
330	3 036-3 237	F	1930	5	self (55) 1985	Lymphoma
331	3 238-3 256	F	1941	0	self (53) 1994	Breast Cancer
332	3 257-3 266	F	1942	3	self (36) 1978	Breast Cancer
333	3 267-3 273	F	?	2	self (?) 1990	?
334	3 274-3 278	F	1942	0	self (47) 1989	Breast Cancer
335	3 279-3 287	F	1915	3	self (73) 1988	Tongue Cancer
336	3 288-3 296	M	1941	0	self (48) 1989	Lymphoma
337	3 297-3 297	F	1922	3	self (60) 1982	Breast Cancer
338	3 298-3 299	F	?	3	self (45) ?	Breast Cancer
339	3 300-3 307	F	1951	0	self (40) 1991	Breast Cancer
340	3 308-3 323	F	1913	4	self (51) 1964	Breast Cancer
341	3 324-3 325	F	1925	4	self (54) 1979	Thyroid Cancer
342	3 326-3 327	F	1981	8	self (6) 1987	Lymphoma
343	3 328-3 331	F	1966	7	godfather	?
344	3 332-3 335	F	1967	1	neighbour	Brain Cancer
345	3 336-3 341	F	1947	3	self (29) 1976	Breast Cancer
346	3 342-3 345	M	1940?	8	self (?60) 1994	Prostate Cancer
347	3 346-3 358	F	1944	4	self (45) 1991	Breast Cancer, Gyn. Cancer
348	3 359-3 364	F	1943	0	father (65) 1968, grandmother 1953	Stomach Cancer
349	3 365-3 379	F	1946	7	husband 1984	?
350	3 380-3 386	F	1937	3	self (52) 1989	Breast Cancer
351	3 387-3 402	F	1952	2	self (40) 1992	Kidney Cancer
352	3 403-3 415	F	?	4	self 1994	Breast Cancer
353	3 416-3 423	F	1940	9	father (58?) 1962	Backbone Cancer
354	3 424-3 427	F	1926	0	husband	Lung Cancer
355	3 428-3 433	F	1944	9	self (46) 1990	Gyn. Cancer
356	3 434-3 435	F	1925	0	self (66) 1991	Urinary/Bladder Cancer
357	3 436-3 441	F	1933	7	self (49) 1982	Brain Cancer
358	3 442-3 447	M	1947	0	self (43) 1990	Stomach Cancer
359	3 448-3 451	F	?	4	self (?) 1982	Skin Cancer
360	3 452-3 461	F	1968	0	self (23) 1991	Lymphoma
361	3 462-3 474	F	1930	0	self (45) 1975	Breast Cancer
362	3 475-3 476	F	1918	6	self (75) 1993	Breast Cancer
363	3 477-3 487	F	1943	2	self (32) 1975	Lymphoma
364	3 488-3 488	F	?	3	?	?
365	3 489-3 495	M	1920	2	self (64) 1984	Lung Cancer

366	3 496-3 500	F	1939	0	mother (56), self (50) 1989	Breast Cancer
367	3 501-3 503	F	1943	2	mother (?) 1992	Pancreatic Cancer
368	3 504-3 509	F	?	9	self	Breast Cancer
369	3 510-3 528	F	1936	0	self (55) 1991	Breast Cancer
370	3 529-3 534	F	1926	2	husband 1986, self (71) 1993	Lung Cancer, Gyn. Cancer
371	3 535-3 535	F	1912	1	self (71) 1983	?
372	3 536-3 551	F	1956	8	self (35) 1989	Breast Cancer
373	3 552-3 566	F	1939	8	self (52) 1991	Breast Cancer
374	3 567-3 573	F	1931	0	godson (30)	Thymus Cancer
375	3 574-3 585	F	1944	3	son (0) 1984	Liver Cancer
376	3 586-3 590	F	1928	3	self (21) 1949	Sarcoma
377	3 591-3 597	F	1966	2	self (24) 1990	Skin Cancer
378	3 598-3 616	F	1956	7	child (4) 1993	Brain Cancer
379	3 617-3 630	M	?	4	self (?) 1991	Myeloma
380	3 631-3 642	F	1933	4	self (53) 1986	Salivary Gland Cancer
381	3 643-3 692	F	1946	2	self (47) 1993	Breast Cancer
382	3 693-3 696	F	1942	?	self (50) 1992	Breast Cancer
383	3 697-3 699	F	1964	2	self (24) 1988	Thyroid Cancer
384	3 700-3 708	F	1929	0	2 x friend, daughter	Breast Cancer
385	3 709-3 717	F	1933	9	self (47) 1980, friend	Breast Cancer
386	3 718-3 726	F	1977	3	self (11) 1988	Kidney Cancer
387	3 727-3 729	F	1922	2	self, father (70), sister	Various
388	3 730-3 734	F	1976	2	self (11) 1987	Kidney Cancer (Wilms Tumour)
389	3 735-3 742	F	1946	0	mother (63) 1992	Breast Cancer
390	3 743-3 746	F	1933	2	self (47) 1980	Breast Cancer
391	3 747-3 750	F	?	2	self 1992	Breast Cancer
392	3 751-3 755	F	1928	0	self (58) 1986	Breast Cancer
393	3 756-3 768	F	1961	2	self (33) 1993	Stomach/Liver Cancer
394	3 769-3 774	F	1938	7	friends, colleagues (14 cases)	Various
395	3 775-3 788	F	1940	0	self (45) 1985	Breast Cancer
396	3 789-3 818	F	1940	3	self (47) 1987	Breast Cancer
397	3 819-3 841	M	1946	3	wife (?) 1993	Breast Cancer
398	3 842-3 857	F	1941	9	self (51) 1992	Breast Cancer
399	3 858-3 863	F	1950	6	self (34) 1994	Breast Cancer
400	3 864-3 873	F	1939	1	?	?
401	3 874-3 880	F	1959	3	sister (50) ?	?
402	3 881-3 935	F	1946	2	daughter (16) 1986	Lymphoma
403	3 936-3 951	M	1934	8	self (31) 1965, (54) 1988	Testicular Cancer, Stomach Cancer
404	3 952-3 954	F	1942	0	self (45) 1987	Breast Cancer
405	3 955-3 955	F	1910	0	self (69) 1978	Breast Cancer
406	3 956-3 963	F	1959	9	daughter (10) 1990	Leukaemia
407	3 964-4 006	F	1940	0	father (72) 1988	Stomach Cancer
408	4 007-4 008	F	1932	3	self (61) 1993	Kidney Cancer
409	4 009-4 028	F	1919	0	husband 1983	Pancreatic Cancer
410	4 029-4 040	F	1933	0	self (57) 1990	Gyn. Cancer
411	4 041-4 046	F	1931	4	son (?) 1963	Brain Cancer
412	4 047-4 071	F	1958	8	self (29) 1988	Breast Cancer
413	4 072-4 073	F	1911	4	husband (72) 1971	Lung Cancer
414	4 074-4 076	F	1912	6	self (72) 1984	Breast Cancer
415	4 077-4 093	F	1920	0	self (63) 1983	Lymphoma
416	4 094-4 102	F	?	1	father	Spinal Cancer
417	4 103-4 112	M/F	?	4	self (man), sister	Oesophageal Cancer
418	4 113-4 123	F	1970	5	father (44) 1985	Stomach Cancer, Brain Cancer

419	4 124-4 150	F	?	4	husband 1988	Skin Cancer
420	4 151-4 158	M	1956?	0	self (29) 1983	Colon Cancer
421	4 159-4 161	F	?	1	self	Colon Cancer
422	4 162-4 180	F	1960	5	mother (71) 1994	Brain Cancer
423	4 181-4 184	F	1959	4	father 1982, self (23) 1982	Lung Cancer/Breast Cancer
424	4 185-4 186	M	1917	8	self (74) 1991	Colon Cancer
425	4 187-4 190	F	1938	5	self (49) 1989	Breast Cancer
426	4 191-4 227	F	1944	9	self (46) 1990	Breast Cancer
427	4 228-4 231	F	?	0	friends	Gyn. Cancer, Breast Cancer
428	4 232-4 238	F	?	0	self	Breast Cancer
429	4 239-4 244	F	1922	0	self (62) 1984	Eye, Liver Cancer, Gyn. Cancer, Lymphoma
430	4 245-4 250	F	1929	6	self (54) 1983	Skin Cancer
431	4 251-4 254	F	1945	9	self (46) 1991	Breast Cancer
432	4 255-4 278	M	1933	2	girlfriend (?) 1993	Colon Cancer
433	4 279-4 281	F	1926	8	father 1948-1955	Stomach Cancer
434	4 282-4 329	F	1930	2	grandmother 1955, father, self	Gyn. Cancer, Intestinal Cancer
435	4 330-4 339	F	1927	4	self (60) 1987	Breast Cancer
436	4 340-4 347	F	?	2	husband 1994	Skin Cancer
437	4 348-4 349	F	?	5	husband 1987	?
438	4 350-4 353	F	1918	6	self (71) 1989	Gyn. Cancer
439	4 354-4 363	F	1919	8	self (?) ?	Breast Cancer, Skin Cancer
440	4 364-4 380	F	1952	6	friend 1962, self (38) 1990	Sarcoma
441	4 381-4 389	F	?	1	self 1984	Breast Cancer
442	4 390-4 418	F	1956	4	self (22) 1978	Leukaemia
443	4 419-4 421	F	?	3	self 1994	Gyn. Cancer
444	4 422-4 423	F	1912	7	self 1984	Breast Cancer, Lung Cancer, etc.
445	4 424-4 432	F	1907	7	self (78) 1985	Breast Cancer
446	4 433-4 441	F	1963	5	father 1986	Stem Cell Cancer
447	4 442-4 455	F	1927	9	self (47) 1974	Breast Cancer
448	4 456-4 458	F	1929	0	self (57) 1986	Breast Cancer
449	4 459-4 462	F	1947	2	self (41) 1989	Breast Cancer
450	4 463-4 482	F	1954	4	self (36) 1990	Gyn. Cancer
451	4 483-4 504	F	1943	0	self (36) 1979	Gyn. Cancer
452	4 505-4 510	F	1921	4	self (64) 1985	Kidney Cancer
453	4 511-4 530	F	1935	2	self	Breast Cancer, etc.
454	4 531-4 535	F	1935	8	self (58) 1993	Breast Cancer
455	4 536-4 549	F	1949	2	self (20) 1969	Gyn. Cancer, Gyn. Cancer
456	4 550-4 552	F	1955	8	self	Breast Cancer
457	4 553-4 560	F	1947	4	self (37) 1984	Breast Cancer
458	4 561-4 569	F	1934	1	self (59) 1993	Gyn. Cancer, Gyn. Cancer, Stomach Cancer
459	4 570-4 577	F	1911	3	father, father-in-law	
460	4 578-4 581	F	1927	6	husband	Prostate Cancer
461	4 582-4 590	F	1933	5	husband, self 1994	Breast Cancer
462	4 591-4 601	F	1950	1	self (35) 1985, father (64) 1991	Lymphoma/Lung Cancer
463	4 602-4 610	F	?	4	husband 1989	Bone Cancer
464	4 611-4 614	F	?	6	self	Lymphoma
465	4 615-4 623	F	1958	0	self (30) 1988	Gyn. Cancer
466	4 624-4 632	F	1928	2	mother (48) 1942, self 1973, sister 1973	Breast Cancer, Gyn. Cancer, Breast Cancer
467	4 633-4 640	F	1958	9	self (32) 1990	Gyn. Cancer
468	4 641-4 646	F	?	6	aunt (67) 1964	Liver Cancer
469	4 647-4 650	F	1942	2	self (42) 1984	Breast Cancer

470	4 651-4 656	F	1931	4	husband	Prostate Cancer
471	4 657-4 658	F	1924	0	self (54) 1978	Breast Cancer
472	4 659-4 663	M	1913	2	self (64) 1987	Colon Cancer
473	4 664-4 667	F	1946	6	self (44) 1990	Breast Cancer
474	4 668-4 680	F	1935	3	self	Leukaemia
475	4 681-4 699	F	1954	5	self (37) 1991	Breast Cancer
476	4 700-4 709	F	1942	8	husband (34) 1979	Brain Cancer
477	4 710-4 718	F	1938	9	sister (42) 1989	Breast Cancer
478	4 719-4 724	F	1932	5	self (31) 1965	Breast Cancer
479	4 725-4 731	F	1931	1	self (57) 1989	Gyn. Cancer
480	4 732-4 739	F	1939	6	self (47) 1986	Breast Cancer
481	4 740-4 741	F	?1962	0	mother (29) 1974	Skin Cancer
482	4 742-4 750	F	1931	4	self (47) 1978	Breast Cancer
483	4 751-4 752	F	1906	6	self (45) 1951	Gyn. Cancer
484	4 753-4 776	F	1917	4	husband (81) 1983	Lymphoma
485	4 777-4 781	F	1937	6	self (59) 1987	Breast Cancer
486	4 782-4 789	F	1940	2	self	Breast Cancer
487	4 790-4 793	F	1930	6	self (50) 1980	Breast Cancer
488	4 794-4 797	F	1952	9	self (41) 1993	Breast Cancer
489	4 798-4 827	M	1931	1	self (46) 1977	Mouth Cancer
490	4 828-4 837	F	1937	3	self (54) 1991	Breast Cancer
491	4 838-4 845	F	1936	7	self (55) 1991	Breast Cancer
492	4 846-4 848	F	1950	5	self (41?) 1991/1992	Breast Cancer
493	4 849-4 864	F	1940	3	self (34) 1975	Breast Cancer
494	4 865-4 867	F	?	2	self 1986	Breast Cancer
495	4 868-4 896	F	1953	6	self (38) 1991	Lymphoma
496	4 897-4 900	F	?	9	self (30)	Thyroid Cancer
497	4 901-4 906	F	1968	6	self (22) 1991	Skin Cancer
498	4 907-4 912	M	1937	8	stepfather (66)	Lung Cancer
499	4 913-4 920	F	1925	2	self (65) 1990	Thyroid Cancer
500	4 921-4 934	F	1961	0	self (20) 1981	Skin Cancer (Basalioma)
501	4 935-4 937	M	1921	4	self (67) 1988/1989, brother	Skin Cancer/Prostate Cancer, Kidney Cancer
502	4 938-4 945	F	1966	0	self (21) 1988	Bone Cancer (Osteosarcoma)
503	4 946-4 951	F	?	5	son (17) 1993	Lymphoma
504	4 952-4 966	F	?	0	self (?) 1990	Gyn. Cancer
505	4 967-4 975	F	1938	3	self	Breast Cancer
506	4 976-4 991	M	1962	7	self (27) 1989	Leukaemia
507	4 992-5 005	F	1969	8	self (23) 1992	Recklinhausen's Disease
508	5 006-5 031	M	1948	4	self (39) 1987	Prostate Cancer
509	5 032-5 036	F	1953	6	father (65?) 1990	Prostate Cancer
510	5 037-5 043	M	1935	4	self (53) 1988	Skin Cancer
511	5 044-5 049	F	1969	4	self (23) 1993	Breast Cancer
512	5 050-5 056	M	1929	4	?	(no cancer)
513	5 057-5 062	F	?	6	father (57) 1952	Lung Cancer
514	5 063-5 067	M	1980	0	self (13) 1993	Lymphoma
515	5 068-5 073	F	1953	2	self	Breast Cancer
516	5 074-5 077	F	1938	2	self	Breast Cancer
517	5 078-5 082	F	1915	3	self (49) 1964	Gyn. Cancer
518	5 083-5 089	F	1930	2	grandchild (5) 1988, husband 1989	Kidney Cancer
519	5 090-5 107	F	1921	2	self (43) 1964	Gyn. Cancer
520	5 108-5 133	F	1937	3	self (47) 1984	Gyn. Cancer
521	5 134-5 145	F	?	1	mother 1993	Colon Cancer
522	5 146-5 155	F	?	1	self 1992	Breast Cancer
523	5 156-5 162	M	1926	3	self (62) 1988	Oesophageal Cancer



524	5 163-5 164	F	?	3	father (66), self 1984	Lung Cancer/Skin Cancer
525	5 165-5 170	F	1923	0	self (59) 1982	Breast Cancer
526	5 171-5 173	F	1940	6	mother 1990	Breast Cancer, Liver Cancer
527	5 174-5 179	F	1965	9	son (2) 1993	Kidney Cancer
528	5 180-5 184	F	1916	1	self (39) 1955	Gyn. Cancer
529	5 185-5 188	F	1922	0	self (71) 1993	Gyn. Cancer
530	5 189-5 193	M	?	0	self (?) 1981, 1993	Oesophageal Cancer
531	5 194-5 201	F	1975	0	self (19) 1993	Gallbladder Cancer
532	5 202-5 204	F	1924	6	self (70) 1994	Breast Cancer?
533	5 205-5 224	F	1949	4	mother (66) 1988	Breast Cancer, Liver Cancer
534	5 225-5 232	M	?	3	self (?) 1992	Prostate Cancer
535	5 233-5 234	F	?	0	self (?) 1988	Breast Cancer
536	5 235-5 248	F	?	6	friend (50), husband	Lung Cancer/Lymphoma
537	5 249-5 250	F	?	9	husband (?) 1989	Lung Cancer
538	5 251-5 252	F	?	3	self (?) 1972	Breast Cancer
539	5 253-5 254	F	?1924	7	self (apx.50) 1970	Gyn. Cancer
540	5 255-5 256	F	1956	0	neighbour (40) 1993	Bone Cancer (Osteosarcoma)
541	5 257-5 262	F	1930	2	self (44) 1974	Breast Cancer
542	5 263-5 280	F	1935	9	self (45) 1979/82, husband 1985	Gyn. Cancer/Lung Cancer
543	5 281-5 293	F	1921	4	self (52) 1973	Stomach Cancer
544	5 294-5 297	F	1928	2	self (44) 1972, grandchild (17) 1994	Breast Cancer/Lymphoma
545	5 298-5 301	F	1922	2	self (59) 1981	Stomach Cancer
546	5 302-5 319	F	1927	3	self (57) 1984	Stomach Cancer
547	5 320-5 340	F	?	6	self 1984?	Breast Cancer
548	5 341-5 348	F	1957	1	daughter (4) 1990	Leukaemia
549	5 349-5 352	F	1944	4	self (39) 1983	Breast Cancer
550	5 353-5 357	F	1942	1	self (47) 1989	Breast Cancer
551	5 358-5 361	M	1930	2	self (60) 1990	Lung Cancer
552	5 362-5 369	F	1954	0	daughter (11) 1994	Leukaemia
553	5 362-5 369	F	1982	0	self (11) 1994	Leukaemia
554	5 362-5 369	F	1977	0	sister (11) 1994	Leukaemia
555	5 370-5 395	F	1930	0	self	Breast Cancer
556	5 396-5 400	F	1923	0	self (66) 1989	Breast Cancer
557	5 401-5 404	F	1944	4	self (32) 1976	Breast Cancer
558	5 405-5 414	F	1955	0	mother-in-law, mother	Stomach Cancer
559	5 415-5 418	F	1911	1	self (45) 1956	Skin Cancer
560	5 419-5 432	F	1951	9	self (23) 1974	Lung Cancer
561	5 433-5 435	F	1930	7	self (61) 1991	?
562	5 436-5 436	M	1930	9	self (53) 1983	Prostate Cancer
563	5 437-5 449	F	1951	9	husband (38) 1987	(MDS-Preleukaemia), Leukaemia
564	5 450-5 456	F	1954	4	self (33) 1987	Breast Cancer
565	5 457-5 481	F	1933	9	sister (?) 1990	Stomach Cancer
566	5 482-5 505	F	1929	8	self (62) 1991	Breast Cancer
567	5 506-5 510	F	1928	5	self (51) 1979	Breast Cancer
568	5 511-5 519	F	1936	3	husband (54) 1984	Lymphoma
569	5 520-5 537	F	1931	2	husband ?/1992	Prostate Cancer
570	5 538-5 553	F	1944	4	husband (34/51) 1977/1994	Lymphoma, Pancreatic Cancer
571	5 554-5 561	F	1968	0	self (25) 1993	?
572	5 562-5 576	F	1932	z (Expatriate)	self (53) 1987	Breast Cancer
573	5 577-5 582	F	1952	2	self (34) 1987, sister 1989, father (70) 1992	Breast Cancer/Breast Cancer/Pancreatic Cancer
574	5 583-5 589	F	1920	3	self (55) 1975	Breast Cancer
575	5 590-5 593	F	1972	0	self (22) 1994	Breast Cancer
576	5 594-5 597	F	1942	8	self (50) 1992	Breast Cancer

577	5 598-5 605	F	?	9	self	Breast Cancer
578	5 606-5 628	F	1961	2	son (2) 1992	Kidney Cancer (Wilms-Tumour)
579	5 629-5 639	F	1927	4	self (65) 1992	Lymphoma
580	5 640-5 662	F	1953	2	self (40) 1993	Leukaemia
581	5 663-5 675	F	1932	1	self (44) 1976	Breast Cancer
582	5 676-5 687	F	1954	1	self (39) 1993?	Breast Cancer
583	5 688-5 696	F	1942	9	self (49) 1991	Breast Cancer
584	5 697-5 701	F	1916	7	self (66) 1982	Breast Cancer
585	5 702-5 703	F	1920	9	mother (66) 1945, sister (50) 1950, brother 1952, sister (60), sister (over 60), sister (approx. 60), sister (44), sister (70), brother (under 70), daughter (40)	Stomach Cancer, Colon Cancer, Stomach Cancer, Stomach Cancer, Stomach Cancer, Stomach Cancer, Gyn. Cancer, Urinary/Bladder Cancer, Stomach Cancer, Breast Cancer
586	5 704-5 709	F	1936	9	husband 1981, self (54) 1990	Bone Cancer/Colon Cancer
587	5 710-5 719	F	1928	3	self (61) 1989, 1991, 1993	Breast Cancer
588	5 720-5 721	F	1922	0	self (45) 1968	Breast Cancer
589	5 722-5 726	F	1936	4	self (55) 1991	Breast Cancer
590	5 727-5 730	F	1926	1	self (52) 1978, 1985	Breast Cancer, Gyn. Cancer
591	5 731-5 734	F	1923	6	self (59) 1982	Breast Cancer
592	5 735-5 739	F	1961	4	self (12) 1973	Breast Cancer (Imaginary?)
593	5 740-5 743	F	1930	8	self (62) 1992	Breast Cancer
594	5 744-5 746	F	1940	9	self (51) 1991, 1994	Breast Cancer
595	5 747-5 747	F	?	0	self (?) 1993	Breast Cancer
596	5 748-5 760	F	1919	7	self (58) 1977, son (?) 1989	Breast Cancer?, Kidney Cancer?
597	5 761-5 765	F	1955	0	self (38) 1993	Leiomyosarcoma
598	5 766-5 794	F	1945	0	self (47) 1992	Colon Cancer
599	5 795-5 806	F	1941	0	self (53) 1994	Leiomyosarcoma
600	5 807-5 821	M	1922	2	wife (45/62) 1972/1988	Gyn. Cancer Etc
601	5 822-5 831	F	1925	0	grandfather (66) 1942, father (49) 1951, self (65) 1990	Lung Cancer/Lung Cancer/Kidney Cancer
602	5 832-5 836	F	1954	0	self (30) 1984	Gyn. Cancer
603	5 837-5 839	F	1938	7	self (47) 1985	Breast Cancer
604	5 840-5 842	M	1907	0	wife 1991	Lung Cancer
605	5 843-5 846	M	?	2	self (?) 1982	Colon Cancer
606	5 847-5 847	F	?	3	self (?) 1972	Kidney Cancer
607	5 848-5 858	F	1963	0	self (30) 1993	Leukaemia
608	5 859-5 867	F	1912	9	self (37) 1949, 1956	Gyn. Cancer
609	5 868-5 877	F	1925	1	self (39) 1964	Colon Cancer
610	5 878-5 882	F	?	4	self 1983	Gyn. Cancer
611	5 883-5 898	F	1937	0	self (26) 1963, mother (47) 1955/1960, sister (30) 1961/1965, sister (33) 1966/68, brother (33) 1971, father-in-law (68) 1965/1971, son (23) 1983, daughter (?) 1990	Colon Cancer, Colon Cancer, Colon Cancer/Gyn. Cancer, Colon Cancer/Lung Cancer, Brain Cancer, Prostate Cancer, Colon Cancer/Liver Cancer
612	5 899-5 925	F	1945	0	self (38) 1983, 1989, 1993/ mother 1955/1961	Thyroid Cancer, Lung Cancer, Breast Cancer/Thyroid Cancer
613	5 926-5 928	F	?	0	self	Breast Cancer
614	5 939-5 933	F	?	9	self (?) 1992	Breast Cancer
615	5 934-5 940	F	1968	2	mother (56) 1993	Brain Cancer
616	5 941-5 953	F	1955	8	friend (38?) 1991	Breast Cancer
617	5 954-5 959	F	1969	0	self (23) 1992	Lymphoma
620	5 960-5 964	F	?	0	self (?) 1966, 1980, 1987	Gyn. Cancer, Skin Cancer, Eye Cancer
621	5 965-5 977	F	1955	8	self (38) 1993	Breast Cancer

622	5 978-5 991	F	1930	4	friend	?	
623	5 992-5 995	F	1973	2	mother (40) 1994	Gyn. Cancer	
624	5 996-6 009	F	1930	6	self (60) 1990, boyfriend 1992	Stomach Cancer/Lung Cancer	
625	6 010-6 011	F	1926	4	self (66) 1992	Breast Cancer	
626	6 012-6 015	F	1939	7	self (45) 1984	Breast Cancer	
627	6 016-6 023	F	1936	9	self (50) 1986	Breast Cancer	
628	6 024-6 026	F	1923?	5	self (65) 1988	Breast Cancer	
629	6 027-6 035	F	1947	1	self (42) 1989	Breast Cancer	
630	6 036-6 045	F	1944	6	self (48) 1992	Stomach Cancer, Perna, Gyn. Cancer	
631	6 046-6 051	F	1948	2	father	Bone Cancer	
632	6 053-6 059	F	1932	0	self	Breast Cancer	
633	6 060-6 078	F	1943	4	self (46) 1989	Lymphoma	
634	6 079-6 092	F	1932	0	self (43) 1975, 1978	Breast Cancer	
635	6 093-6 118	F	1920	6?	grandmother 1982/1984	(62) Stomach Cancer?	
636	6 119-6 120	M	?	7	self 1960	Tongue Cancer	
637	6 121-6 125	F	1913	0	self (69) 1982/83?	Breast Cancer	
638	6 126-6 138	F	1944	2	self (49) 1993	Colon Cancer	
639	6 139-6 140	F	1906?	2	self (70) 1976	Lymphoma	
640	6 141-6 141	F	?	4	self (42) ?	Gyn. Cancer	
641	6 142-6 145	M	?	0	self (?) 1993	Pancreatic Cancer, Duodenal Cancer, Spleen Cancer	
642	6 146-6 153	F	1952	0	self (37) 1989	Breast Cancer	
643	6 154-6 166	F	1931	0	self (58) 1989	Breast Cancer	
644	6 167-6 170	M	1912	0	self	Breast Cancer	
645	6 171-6 174	F	1930	0	self (61) 1990	Breast Cancer	
646	6 175-6 181	F	1941	7	self (40) 1981	Breast Cancer	
647	6 182-6 182	F	1924	8	self	Breast Cancer	
648	6 183-6 194	F	1929	3	self	Breast Cancer	
649	6 195-6 197	F	?	0	self (?) 1992	Breast Cancer	
650	6 198-6 220	M	1918	3	self (62) 1980	Colon Cancer	
651	6 221-6 223	F	1924	0	self (65) 1989	Breast Cancer	
652	6 224-6 229	F	?	0	husband (66) 1980	Lung Cancer	
653	6 230-6 231	F	1978	0	mother (?) 1989	Gyn. Cancer	
654	6 232-6 237	F/M	?	6	self 1990, grandchild (15) 1990	Gyn. Cancer?/Leukaemia	
655	6 238-6 243	F	1925	7	self (52) 1977, 1984	Rare Cancer	
656	6 244-6 252	F	1929	0	self (30) 1959	Breast Cancer	
657	6 253-6 256	F	1917	8	mother (65) 1950?	Gyn. Cancer	
658	6 257-6 263	F	1920	7	self (54/74) 1974, 1994	Breast Cancer, Colon Cancer	
659	6 264-6 270	F	1935	3	self	Breast Cancer	
660	6 271-6 279	F	1943	0	self	Breast Cancer	
661	6 280-6 286	M	1935	7	father 1952	Lung Cancer	
662	6 287-6 298	F	?	0	self 1993	Gyn. Cancer	
663	6 299-6 314	F	1924	2	self (49) 1973, 1992	Throat cancer	
664	6 315-6 318	M	?	3	self 1987	Urinary/Bladder Cancer, Prostate Cancer?	
665	6 319-6 326	F	1952	6	self (35) 1987	Gyn. Cancer?	
666	6 327-6 329	F	1933	3	self (47) 1980	Gyn. Cancer	
667	6 330-6 339	F	?	z (Expatriate)	self 1982	Brain Cancer	
668	6 340-6 346	F	1934	0	self (45) 1979	Breast Cancer	
669	6 347-6 352	F	1919	0	self	Breast Cancer	
670	6 353-6 360	M	1944	0	self (48) 1992	Throat Cancer	
671	6 361-6 379	F/F	1936	0	friend, mother 1979/1992, father (80) 1991, neighbour 1993	Breast Cancer/Pancreatic Cancer/Stomach Cancer	
672	6 380-6 384	F	1925	0	self (62) 1987	Gyn. Cancer?	

## Appendix 1



KIRJOITA  
*kokemuksistasi,  
ajatuksistasi ja  
tunteistasi –*

OSALLISTU  
KIRJOITUSKILPAILUUN

**Kun sairastuin  
syöpään**

Sairastuminen pitkäaikaiseen ja vakavaan sairauteen voi muuttaa ihmistä ja hänen arkielämäänsä monin tavoin. Syöpäsairauksia kohtaan tunnetut pelot aiheuttavat myös potilaiden läheisissä huolta. Kuntoutumisen kannalta on osoittautunut hyvin hyödylliseksi vaihtaa kokemuksia muiden potilaiden kanssa siitä, miten sairastumisesta ja sairauden kanssa elämisestä selviydytään. Kokemusten kirjoittaminen voi myös selkiyttää omia ajatuksia sairastumisesta ja sen vaikutuksista itsen ja lähiympäristöön.

KIRJOITUSKILPAILU 1.5.-30.9.1994

**KILPAILUN TARKOITUS**

Suomen Syöpäpotilaat ry haluaa näin kerätä syöpään sairastuneiden itsensä kertomina potilaiden omakohtaisia kokemuksia ja ajatuksia. Tarkoitus on koota parhaista kirjoituksista julkaisu, jonka välityksellä syöpäpotilaat ja heidän läheisensä kertovat keinoista selviytyä sairauden aiheuttamista ongelmista.

Myös omaiset tai muut läheiset ovat tervetulleita osallistumaan kirjoituskilpailuun. Kirjoituksen voi otsikoida itse.

Kuvat: Gorilla / Sari Poijärvi, Aimo Hyvärinen

## OMAKOHTAISUUS JA AITOUS RATKAISEVAT

Kilpailuun osallistuvien kirjoitusten arvoa ei ratkaise oikein kirjoitus tai käsiala vaan omakohtaisuus ja aitous.

Voit otsikoida kirjoituksesi haluamallasi tavalla.

Kerro omalla tyyllilläsi kokemasi tai läheisesi kokeman sairauden aiheuttamista tunteista.

Kerro sairastumisen/sairauden mahdollisista vaikutuksista ihmissuhteisiisi: miten perheenjäsenet, ystävät, työtoverit sairauteesi suhtautuivat?

Onko sairaus muuttanut minäkuvaasi? Jos on, kerro miten.

Halusitko, kykenitkö kertomaan sairastumisestasi muille?

Kerro omista keinoistasi selviytyä sairauden aiheuttamasta kriisistä.

Keneltä sait tukea? Keneltä sait lisää tuskaa, miksi arvelen sen aiheuttajan näin käyttäytyneen?

Kerro, miten koit hoitohenkilökunnan suhtautumisen itseesi ihmisenä, potilaana. Oliko olosi turvallinen, saitko riittävästi tukea ja tietoa?

Parantaako aika? Voiko luottaa siihen, että ajan myötä tapahtuu sopeutumista? Jatkuuko elämä ennallaan toipumisen jälkeen?

Miten selviydyt sairautesi kanssa?

## KILPAILUN PALKINNOT

- I palkinto 3.000 mk**
- II palkinto 2.000 mk**
- III palkinto 1.000 mk**

Muiden vastanneiden kesken arvotaan viisi 500 markan palkintoa.

## ARVOSTELULAUTAKUNTA

Puheenjohtaja *Terttu Mertanen*, Suomen Syöpäpotilaat ry:n puheenjohtaja, koulunjohtaja

Kansanrunousarkiston johtaja *Pekka Laaksonen*, Suomalaisen Kirjallisuuden Seura

Lääketieteen ja kirurgian tohtori *Anneli Vainio*

Toiminnanjohtaja *Pia Ullberg-Hakulinen*, Suomen Syöpäpotilaat ry

Kuntoutussuunnittelija *Leena Siren*, Suomen Syöpäpotilaat ry

Arvostelulautakunnan sihteerinä toimii tiedottaja *Marja Kalliala*, Suomen Syöpäyhdistys

## TULOSTEN JULKISTAMINEN

Kirjoituskilpailun tulokset julkistetaan Syöpä-lehdessä, joka ilmestyy loka-marraskuun vaihteessa 1994. Voittajille ilmoitetaan kirjeitse.

## AINEISTON TALLENTAMINEN

Aineisto tallennetaan Suomalaisen Kirjallisuuden Seuran kansanrunousarkistoon.

## KILPAILUN JÄRJESTÄJÄYHTEISÖT

Suomen Syöpäpotilaat ry, Suomen Syöpäyhdistys ry ja Suomalaisen Kirjallisuuden Seuran kansanrunousarkisto.

## VASTAUSOHJEET

Merkitse kirjoituksen alkuun

- oma nimi
- ammatti ja koulutus
- syntymäaika ja -paikka
- osoite ja puhelinnumero
- maininta siitä, voiko kirjoituksesi tai osia siitä julkaista, jos tunnistetiedot hävitetään (= huolehditaan siitä, ettei kirjoittajan henkilöllisyys eivätkä muut kirjoituksessa mainitut henkilöt ole tunnistettavissa)
- kilpailuun voi osallistua myös nimimerkillä. Mahdollisen palkinnon varalta nimi- ja osoitetiedot on tällöin syytä liittää mukaan.

## KIRJOITA

- enintään 50 liuskaa
- mieluiten koneella, mutta voit kirjoittaa myös käsin
- suomeksi tai ruotsiksi
- normaalikokoiselle paperille (A4)
- vain paperin toiselle puolelle
- jätä liuskan vasempaan laitaan leveä marginaali (esim. 4 cm)

## KILPAILUUN LIITTYVIIN KYSYMYKSIIN VASTAA

tiedottaja *Marja Kalliala* puh. toimeen 90-13533265, voit soittaa myös kotiin iltaisin puh. 90-1357191

Lähetä kirjoituksesi osoitteeseen

Suomen Syöpäyhdistys  
Tiedottaja *Marja Kalliala*  
Liisankatu 21 A  
00170 HELSINKI

Merkitse kuoreen nimesi ja osoitteesi.

Kirjoituksia ei palauteta, joten ota itsellesi kopio.

**LÄHETÄ KIRJOITUKSESI VIIMEISTÄÄN 30.9.94.**

## Appendix 2

### Seth's story: Some indistinct ideas and reminiscences on cancer

[the moment of diagnosis]	[1] "Oh well, there will be a surgery for sure." I heard doctor's surprised sentence behind me. I was lying, a cheek pressed against the polyclinic pillow, endoscope tube in my bottom. The physician looked into it as though it were a telescope, a [way into] inner space. An amazed, almost a frightened tone in the doctor's voice, gave me a feeling of relief. My long personal nightmare was over. There was something that a specialist could detect. A desperation, spleen, dreams, the feeling of helplessness were not only the results of my bad nature or imagination. "There is a growth, I cannot tell yet what kind, but it bleeds" the doctor continued. I knew it was malignant. I had felt it long enough. It was a relief, a month-long problem with haemorrhoids was over. Plain haemorrhoids would not manage to ruin the whole <i>soma</i> . <u>Half a year confusion, collapse, the feeling of apocalypse, desperate depression had a confirmation: Growth! I came down from the examination table almost happily and pulled up my pants. Feeling relieved I made a date for the next polyclinic visit.</u> They would call me if there were something to announce before that.
[individual feelings and natural surroundings]	[2] Light snow was falling on asphalt; the sky was bluish grey as I walked out of the doors of the chirurgic hospital. Now life at least belonged to me. I was at least someone. Something had happened to me that did not happen to everybody at this age. I felt myself too young and at the same time ready for the grave, both at 29 years old. <u>What could have been the reason that life, which despite the years I felt was barely beginning, could stop already? What, yes what? I did not understand.</u> Tram number ten turned into the stop. The vehicle and the few people sitting in it, the almost silent streets of Helsinki, the chilly frosty weather. Everything felt too ordinary, but at the same time festive. It was the feeling of a young man carrying death inside him. I felt like having coffee and buns.
[pre-symptomatic health concerns]	[3] A half a year before that, work things began to make me nervous, and I reacted all the time with my stomach. I had to survive every day. The work felt more and more insane. I knew that it had something to do with being tired and depressed, but usually I was so involved with my feelings that the lack of sense and completing the tasks filled the days.
[the smell of illness]	[4] One night before going to bed, my wife told me to take a shower, you stink. I had been sweating, I smelled it myself, the sweat smelled like insects. This is some kind of fear. I knew the smell of sweat changes through life. I took a shower. I remember the smell of falling ill and the darkness of that night.
[pre-symptomatic health concerns]	[5] I fought until spring. Stressed, pissed off, easily irritated, waiting for the summer vacation. Everything felt wrong, overwhelmed by the weakness of existence. I could not change anything, not make it better at least; dissatisfaction; looking for whom to blame was a daily thing. [6] I waited for the time I could go to my summer house, the vacation. There, I get better. Every summer I had recovered from the lack of energy wasted during the winter. I took some additional unpaid vacation, which was fine for my employer. There was a long summer waiting ahead, and the pleasure of sauna on the lake shore. Mowing, berry-picking, piece and nature, birds singing and lots of small tasks to solve as one likes and can. I knew that by Autumn everything would be different, my mood would be better. Birds were singing, mild summer wind blew in the trees, I sat in the outside toilet, door open, enjoying nature and the summer. I had noticed that I had to visit this place way too often. It felt like I had to run there all the time. "Is it the vacation, holiday food, winter stress." At the end of the summer I sat there really astonished. The insects did not calm down. "It takes so long. My stomach has become only worse. In the city I shall visit the doctor, now it's the rotting month and

	<p>maybe that's it. Always everything that comes also passes. Fresh air will do some good anyway. The main thing is I am not afraid of autumn", I thought.</p> <p>[7] The autumn in the city was warm. The summer seemed to be continuing. The tiredness did not disappear. I continued to visit the toilet all the time. Finally I had to go to the healthcare centre to complain, haemorrhoids. I related the symptoms and the physician prescribed baths. I felt as though I had a small fever all the time, or from time to time.</p> <p>[8] I cannot remember how I managed with my work. There were new people working. I was like a strange and old employee who does not manage with his tasks. I was bad. I, who in my opinion had been doing a lot to be good and manage well with work challenges. Now I lacked the energy, I was absent minded, bad natured even. I did not manage at all. For a young person it does not look right or is hard to imagine this as a result of illness. Evil, really evil.</p>
[pain story]	<p>[9] Then the pain began. It got worse day after day. Somewhere between rectum and leg. A twinge that continued for weeks. The doctor visits. Haemorrhoids only. (The growth was pressing against the nerves). One beautiful autumn morning has stayed in my mind, I walked out into the street, the sun was shining, trees in the park were yellow. Life and my condition were fine. There was no visible reason for being happy. In the tram I noticed that the twinge was gone. I remembered that when it came back. I was down and broken.</p>
[suffering alone]	<p>[10] Work was unsuccessful, my wife was nervous about my condition. Did she think that this must be some kind of neurosis or something. My wife came home from work one day. I had already come in a couple of hours earlier, I sat and suffered from pains. I did not know what to do. The doctor's appointment was at the end of week. The full desperation and physical agony had controlled my mind. I sat and looked at her. I noticed how she got scared as she saw my look. I knew what look it was. A look frozen by agony begging for mercy. It was the same that my father had had few weeks before dying from cancer. The pain was harsh, but still you do not want to accept death as a matter of fact, although you know it is approaching. I had to hide my agony and act as though there was nothing big going on. I would go to the doctor on Friday and complain as carefully about my problems as I can.</p>
[dream experience and interpretation]	<p>[11] <i>Help, an explosion, I got hit, shrapnel. It had torn my stomach, the arm hurt, it was dark. Where was everyone. I remembered that I slept in a dugout and a bomb shell had torn apart my stomach. I was wrapped in sheets. Was I in the troop first-aid station already.</i> The night light was beside my bed. War. Morning broke in the hospital. Other patients in the room were still a sleep. I remembered being in the hospital. Yesterday I had the surgery. It felt empty where my stomach was. The painkillers cleared my thoughts, the body that is my own life was dependent on a dripping bottle. I recalled yesterday. In the clinic ward there were at least 20 patients, some of whom had had their surgery yesterday. The ones who had been there already for a week looked at us with pity and understanding. They knew what it was and what was coming. This day was everything for me. I had already slept for a couple of hours. Where did this image of war come from. The day before I had read in the <i>Seura</i> newspaper about a new play called <i>Unknown Soldier</i> in the city theatre, the characters and rehearsals. This was my private war. You have it despite the era, the blight of every generation. Everybody must define his or her own position in life's battle on a personal level.</p>
[self-negotiation in hospital]	<p>[12] I laid there and thought, what would I give for not having that day; a lot and nothing. This moment was everything I had. If I will not survive it, I will not survive at all. The next surgery patients were brought in. Carrying surgery clothes. I was forced to give my body into the hands of others. Being on a narrow surgery table having on only surgery gown was a surrender, donating your body to the hands of professionals. They did their work, I gave my whole life. At this point I had no demands. I trusted.</p>
[individual feelings and natural surroundings]	<p>[13] Feeling fine I looked at the wooden columns in the surgical clinic. The nice wooden carvings curved masterfully. What a weight those columns could carry. The whole weight of the building with great harmony. How humans master it. Being intoxicated I was enjoying the beauty of human craft. "That there can be something so genial and beautiful." I stared at this wonder for hours. The nurse came to ask how I was doing. I was on the top of my life. Not ill or anything. Fixed at once, I</p>

	<p>could go anywhere I wanted. So well things had turned out. I smiled happily. I was healed from all my troubles in one day. I fell a sleep.</p> <p>[14] My friends were beside my bed when I woke up. Everything was fine. I must become well now.</p>
[self-help]	<p>[15] On the next day I had to walk some steps. It felt like a line of knives in my stomach. The wound is healing I tried to think. It was the time for physical pain. This was pure pain. Knives in the stomach. I did not want to take the painkilling shot. I tried to keep it for later, hoping it would help to cure me as long as I managed to survive the ache, before the shot was given and closed me in cotton.</p>
[religious experience]	<p>[16] It was dark, it had been raining outside, now there was fog. The patients' hall was quiet. Carefully I pulled myself up with the IV stand to look out of the window. A November evening in Helsinki. On the wall of the opposite house was a white being. I looked more carefully. This was a Christ. A monument that was there wishing everlasting and continuing blessing to human kind. I had never before thought about religion in such a tangible and personal way. How much suffering everyone in here had to soothe by themselves. Yes, in you and in me; in everyone of us both in friends and enemies. We were all here. There had to be some power and it had to be coming from somewhere. The old sources were finished from my side. The fog made the white monument' surroundings glow with some light. This was like a vision.</p>
[life in hospital]	<p>[17] Before going to the hospital I had been thinking of reading and writing my diary, but no chance for it. Being ill was daily work. Food, cleaning, toilet, medicine, shift changes, day, night, visits. That is it, at most waiting to go home.</p>
[Patient-doctor communication]	<p>[18] Doctors visit. The group around my bed, everyone looking at me. The caring doctor stays to explain my situation. They had removed some suspicious glands at the same time, the results come in the end of the week. "So there was something to wait for. The information comes on Thursday."</p> <p>[19] On Friday I asked for the results, as no one told me anything on Thursday. The doctor promised to come later to give me the results. There was something to tell. I knew. I was ready. To take even death from life. We went into the procedure room. There was only one chair, the doctor asked me to sit on the edge of the bed. He sat on the chair, lower than I. He was few years older than I. It was a difficult thing to tell. "Having such profession you get harsh, you see so much, everyone has something", he began. I saw that he was comparing himself with me. I felt sorry for him, I appreciated his work. I knew he got fine compensation for it, but I myself would not have been able to do the doctor's work whatever the money was. "We found something in those glands", he managed to say. "What should I do and will there be some additional treatments, I asked for continuation treatments." I knew I did not want to have any more treatments. This surgery was in my opinion enough, I could not take more. "Tumours of this kind are not curable with X-ray treatments, so we just follow how it is developing." "Does the food have some significance?" I asked. "You can eat bran, it has some significance", the doctor advised. I thanked him and was relieved. No more procedures.</p>
[evaluation: post-recovery time]	<p>[20] The clouds were travelling from west to east. I looked at the fair weather clouds, their golden edges lit by sun against the blue sky. The clouds took new shapes, new faces until the whole shape was new. I had looked at it for a long time, without the feeling of losing time. I remembered doing the same thing as a child. I was in a similar state of mind. K. asked me for coffee. The clouds at the summer house. Half a year had passed after the surgery. K. said that, "you have learned to hang around, before you could not do it at all. You had to do something all the time, fix something, make something." I had made a decision to survive this summer. "Next summer, even, even if it is the last", was my thought back then in the autumn, after the surgery. Now it was here and I looked at the fly on the window. The grass was green.</p> <p>[21] Last winter after the illness leave I did not feel like working. My memory was bad. The result of anaesthesia and medication I suppose. Acquaintances and work colleagues were shocked hearing about my case. Certainly they had almost buried me and created a tragic story on the top of it. But I lived and after the illness leave I returned to work and blamed others for oversights that had taken place while I was away. I think that before I had been too kind, I made promises and I could not say</p>



	no. As I did so, I did it too harshly. Now I decided that this comes to an end. I did not give a shit. I didn't have much to lose. I had decided to have the next summer to myself, free and in my summer cottage.
[the meaning of cancer]	[22] I could not stand a busy life. I reacted as if I was allergic to it. I lost the point, the attachment that made me function frantically. I had lost the habit to live in a hurry, I was recovering. I could not escape into a busy life, I still cannot do it. I felt that being busy was a sin, a way to pass the moments. I noticed that people who were not constantly in a hurry managed just as well.
[evaluation: post-recovery time]	[23] During the winter my mind was busy with questions, how life can be so short, thirty years of human life is nothing. I was just at the beginning. At first the elementary school and the gymnasium. Now they tried to push in my hands the graduation papers of life, although I felt I had not even entered it yet. Now I should have the courage to make things true, as I had dreamt when I was young. Make dreams true. I started to work partly because I decided to work and learn. A donkey following the carrot. I had courage, now or never was tapping at my work table with its fingertips, through my window were some garbage bins and the wall of a factory. Here sat a man with his destiny. Waiting for ever was no longer possible; but first, the summer. I'll do it if I am still alive, after a year or something like that. Was there some decisiveness, a contract with life, I'll do that first and then things will happen or not. I began to gather courage with the back ends of my mind. With losing your life you'll gain it. Could a win be a loss? I felt that the ceiling of my office hung like bellows strings, like a lunar landscape. I observed it long moments and let my thoughts flow.
[self-help]	[24] "Bran!" I recalled doctor saying: "It might help." Short life, so short that it is not explainable. In such a short time I was not ready for heaven, despite whatever sins would have been forgiven. I did not know how that I had come here or why I was as I was? What character had my nature, thoughts? Was I just a product of environment, who was I? Nothing can be explained plainly by birth and death. People came from somewhere and somewhere they go. This story is longer, not just a beginning and end. I ate bran.
[conclusion: the meaning of cancer]	[25] The cancer was discovered approximately fifteen years ago. Since then many things have happened in my life. An unsuccessful business, divorce, studies, a change of profession, loneliness, travelling, life abroad, unemployment, some brief moments of happiness: everything that belongs to this life. I do not feel that I am living under some kind of protection, that I can safely recall and analyse the truths of life. The other way around, in fact. I can note that falling ill is still the most precious experience that I have had in my life. I experienced something when I was young. I got some perspective and the kind of depth that usually comes later. Clearly I can note that cancer is the best and worst thing that has happened in my life so far. My most precious experience.

## Hanna's story: What did I think before I fell ill with cancer?

### FOR INFORMATION

I send my writing so late as I have been really busy at work – I hope it helps when you select materials for your book. I remind you that I wish to use a writer's name if you publish the text. Is my writer's name too long?

- [The time before the diagnosis] [1] Precisely seven years ago I had my 30th birthday. The day was really rainy, in the kitchen two mothers of my age waited for party coffee and on the floor three six-month-old babies tried to make each other's acquaintance – my own daughter was annoyed and tired like me. I had just made an appointment at my gynaecologists and I was still wondering if it was reasonable to visit a doctor based on such unsure symptoms. I wished that the neighbours would drink their coffee fast or the babies would make such a fuss that I would get rid of my guests and think about my situation in peace.
- [Pre-symptomatic health concerns] [2] Already a couple of months after birth giving I had felt a bump in the lower part of my belly. After the birth a gynaecological check-up revealed that my uterus was not shrinking well and I was given some medicine. This information was enough for me during the summer. Later in the summer my sister asked if I was expecting another child. I was a bit upset and told her that I was, and that my weight had dropped compared to the time before pregnancy. A bit later I noticed that I could not lay on my stomach when I played with my child – I had to keep my backside a little higher and turn myself to the right because something was pressing in the stomach. My husband also felt that the stomach was a bit weird when he pressed it with his hands. This was the knowledge that made me call for a doctor's appointment. I also said that I was feeling dead tired - by accident I chose the right expression to describe my feelings. Whenever possible I slept. I fell into sleep that felt endless and impossible to wake up from. I argued with the doctor that it was connected with childcare, although my daughter was well behaved and let me sleep and my husband helped with everything.
- [The moment of diagnosis] [3] A week later I visited a private doctor. As the internal check-up began, the doctor literally turned white: "The right side is fine...but...on the left there is an ovarian growth! It grows here under the uterus." I understood the reaction of my long-term gynaecologist – her daily job was at the cancer clinic. The ultrasound examination that was done the following day did not give any clarification of the nature of the growth; the general conclusion was that the growth was big, but no way was it cancer. I was referred for surgery at the cancer clinic. More studies at the clinic did not bring any new knowledge, and the structure of growth stayed unknown. The doctors found out the truth in the surgery room, and me a day later when I was awake enough after a long anaesthesia and painkilling shots.
- [Patient-doctor communication, the moment of diagnosis] [4] The female surgeon kept her hand on my knee and looked aside slightly saying briefly that the growth was bigger than expected, that it was a cancerous growth and the uterus and ovaries had to be removed, as malignant cell mutation had also taken place on the right side. The surgeon said that everything was removed and the growth had not been attached to anything, although it was 15x20 centimetres – almost as big the head of a new-born baby! The doctor realised she should shut up, so I had time to understand. "Now it is in me", was my first thought.
- [The meaning of the illness] [5] I was not then, and I have not been since, bitter because of my illness. I have never asked myself why, exactly, I was the one to fall ill. If I thought that way, I would have wishes someone else was ill instead of me. I was satisfied when I found such a human side in me.
- [Talking about cancer to her husband] [6] I asked the doctor to call my husband so I could explain the situation to him myself. The situation was dream-like; our happy baby waking in her carry-cot, my husband on his knees crying beside my bed trying not to push the tubes that crossed the bed, I was swollen and carried away because of the medication. I assured him that the surgery was successful. However, at the same time, I had to admit that I was about to start with cytostatic cures and so we should not make any long-term plans. My husband told me later that after coming home, he had been cleaning for two days, crying when the sound of the vacuum cleaner was loud enough.

[The treatment]	[7] The phase of uncertainty known to all cancer patients, which never ends fully, began in our lives. I felt extremely sick. After childbirth the ovarian cancer had developed at extreme speed and took away my energy. I had had no rest since giving birth, breastfeeding had demanded its part and now fear of the future strangled both of us.
[Talking about cancer to others]	[8] I talked about my illness only to my siblings and some close friends. I forbade them to talk about it, but the harm had already been done. My sister in law did not listen to my request and she talked about me to a female relative even while I lay in hospital! That was a big shock and offence for me. At the hospital this was my greatest sorrow. I was angry because this thing that I could not understand myself was part of daily discussion already. I closed my relatives' mouths with one brief and angry phone call to my sister in law. Since then she has never asked how I feel.
[The significance of social support]	[9] My being ill happened at the time when the state generously supported families with children. When I went to hospital I always got a babysitter – something that really helped me. The biggest help for our small family came from the godmother of our child, a friend from my study days. She left her work to take care of me and the child during that time! She lived with us, we took care of housework and I could rest and take walks as I felt. For me the situation was ideal, because my husband had to travel a lot for work and make rather long days. Year after year I become more and more convinced that the help from close friends in these first months saved our family from many sorrows later. We both had time to suffer and pull together our strength without being worried about taking care of the baby or cooking. Organising daily life sometimes takes more effort than fighting illness. Our friend was also an exceptionally happy and compassionate person so being with her brought some colour and new ideas to an otherwise closed home. We did not need others.
[Self-help]	[10] I carefully followed the doctor's orders regarding walking outside. I pushed the pram along smoggy and rainy paths and tried to understand what exactly the doctors meant by not making any long-term plans. They suggested concentrating on gathering strength for the next treatment. Naturally it was good that the doctors did not promise I would be cured at the beginning, as they were equally unaware of the outcome.
[Thoughts about dying and death]	[11] <u>During the autumn I organised the funeral in my mind.</u> Particularly when walking, I prepared various <i>in memoriam</i> speeches and farewell occasions. I thought how shocked my colleagues would be as they received the news of my death. I cried at my own thoughts, but luckily the days were grey, so passers-by did not pay attention to my red nose. There were opportunities to tell people about my illness, but at my workplace there was no one suitable. I did not want then, and I do not want now, my workmates to check my wellbeing and ask, in awkward situations I suppose, about the course of my illness. The self-pity walks worked. After those I was for some time fed up with the subject, hungry and tired, so in this way a couple of hours passed again as they were supposed to.
[Biomedical treatments and self-help]	[12] I was treated with chemotherapy once every four weeks, the procedure lasted half a year and then I had follow-up surgery. After eight weeks of sickness leave I weighted 49 kilos, I had lost six kilos. I looked like a pile of dried bones – sometimes I felt like a convict in a concentration camp. There is no need to describe feeling sick and examinations – everyone who has been in hospital is aware of them and there is no point scaring new patients. Whatever the illness might be, becoming well is largely based on one's own will. I made it clear in my mind – the doctors take care of their part and I mine. For example, if I had not been forcing myself to eat healthily between the therapies, the bad blood counts would not have allowed new cytostatics and the treatments would have been cancelled. Logic, but so hard! I still did not want to be totally helpless, because I saw many people in far worse conditions and even they did not give up. Of course, I did not believe that one can stop cancer spreading purely by will power, but at least I could control my recovery. [13] As I already wrote, the attention I needed, I received from my family circle. This solution was fine for me, and I supposed that this was the reason that I was not asked if I needed practical help. More than help at that moment, I missed conversations about marriage and my sex life: pregnancy, giving birth and falling ill, we had had no sex for more than a year. In my thirties I had no periods, only a vagina, and I took oestrogen every day to keep away the menopausal symptoms. After the treatments and sickness leave were over, I realised that no one had given me any kind of informative leaflet to read about such radical surgery and its influence on the life of such a (young)

	<p>woman. Supposedly there was no such thing. As I had no insuperable difficulties, I did not care to return to the question during the follow-up visits to the hospital. These brief visits, to often-changing doctors at cancer clinics, do not really give an opportunity for such conversations.</p>
[Patient-doctor communication, the need for psychological support]	<p>[14] No one ever asked how big a loss it was to not be capable of having a second child. I had had a miscarriage earlier and now we faced a different sorrow, we craved our lost opportunities. In my opinion nurses, and particularly my personal nurse at the N. Clinic, should have brought it up as I did not know about this myself. Even a short conversation would have helped to clear my mind and give some basis for the discussions at home.</p>
[Returning to work]	<p>[15] After intensive care that lasted less than a year, I recovered. I went back to work, where no one could remind me of it, because they thought I had had been on maternity leave. Since I fell ill I think about my condition ALL THE TIME – the only moments I forget about it are when I take care of my child. I wonder, will I ever be able to push my illness aside. Being at work began to fill my thoughts so I had other things to think about as well.</p>
[The significance of cancer]	<p>[16] <u>Until now there has been not a single day without having cancer in my mind (and hardly will there be one).</u> I am sure it does not affect my actions. I am not spiritually down, I do not have nightmares and I am not afraid of falling ill again. However I know that I prepare myself for the moment when the illness returns. I could adapt the old advertisement for Flora: What did I think before I fell ill with cancer?</p>
[Concerns about her child's future]	<p>[17] <u>I have began to prepare my daughter for this kind of illness. This has happened without noticing it.</u> I told her carefully about my friends who have cancer and about one who passed away because of it. At the same time I have explained that one's own lifestyle means a lot, but at hospital they help everybody. Our little daughter misses a sibling a lot, but she has been satisfied with explanation that mother's stomach is so ill that new baby cannot grow there. I tell her everything, as her comprehension is sufficient and fear will not take over.</p>
[The importance of taking care of oneself]	<p>[18] The life has settled, my marriage is fun and my physical condition seems to be improving. In <u>following the condition and my feelings I have perhaps gone too far, I will not observe my condition alone for a long time.</u> But who would send me to examinations if I would not go to the doctors of my own accord?</p>
[Concern about the future]	<p>[19] During the summer I have had some stomach pains and three brief episodes of fever – the results come tomorrow. At this point the familiar fear is in my mind... hopefully tomorrow at that time this will be over.</p>

## Ruth's story: Melanoma and I

[The meaning of cancer, cancer aetiology]

[1] When I hear the word melanoma it feels like a death sentence has been declared, but when it is going to be acted upon is not clear. This is what I have thought. I do not know how others experience it. Perhaps my own fear comes from the times of my studies. When I studied to become a nurse we had a lecture on melanoma. Regarding its different forms and classifications and how bad the chances are for people with it. So it happened that my own fear came true. Could it be that what you are afraid of most, you will face in your life? Could one talk about Karma – these are thoughts affecting one's destiny.

[Individual lifestory]

[2] It was the first working day after the Midsummer festivities 1993. The phone was ringing, I went merrily to pick up, I was really in a good mood. I had had a wonderful summer holiday and I was in love, and there was still some vacation left. Everything felt so unbelievably good – although before the summer vacation I had had a miscarriage – that I did not want anything to happen to change this. I had tried to have a child for ten years and now; when I had become pregnant it felt it was a small miracle. But I had lost that miracle and that hurt. I have one grown up son, a son who follows his own path. Therefore, a small sweet-smelling bundle would have been a present from heaven. In my uterus a large benign growth remained that had caused the miscarriage. There were no options other than the removal of the uterus. I was waiting for notification from hospital regarding the procedure.

[The moment of diagnosis]

So, I went to answer the phone. I picked it up and at the other end was the physician from our workplace. I realised in a moment what it was about. I felt dizzy. I realised on the spot that the almost insignificant birthmark had turned out to be malign melanoma. I was home alone. I fell on the floor, I heard as she continued: I will write to the central hospital, in two weeks they will send you an invitation. They must replace some skin on your legs, because normally they must remove lots of tissue and perhaps there will be some chemotherapy given as part of the continuation treatments. I listened to doctor's speech without saying a word and noted: I am totally puzzled; this was the only thing I was able to say throughout the phone conversation. The doctor understood fully – at least I assumed – how I felt. I put down the phone. My life was filled with emptiness. I felt as though I was dying on the spot, or actually I was thinking that I cannot die, because I am fully healthy, happy and so energetic. I denied the whole thing. In reality I began to moan at myself immediately. I sensed a terrible feeling of chaos, so I could not even cry. In a moment I planned my own funeral so my son would have nothing to organise and no extra costs. He had been unemployed for a long time and because of this his life had slipped from its track. Drinking had taken over. But now, when he hears that I have cancer, will he become a total alcoholic, or will he stop drinking? They say that by falling ill people control their surroundings.

So, I think – how am I going to tell my son this. He has already lost all his dear ones, most recently his own father in spring a few years ago. My son who had a dark childhood that lasted most of his life. People bullied him at school – kicked to bruises, money blackmailed, experienced a marriage crisis, whatever. Now this. Oh dear creator, I prayed to God for power. And how should I tell my boyfriend? His brother died of melanoma. In spring, when I met my current boyfriend, the first thing he told me was about his brother. The brother had lived only half a year after he was diagnosed with melanoma. This had been a hard time for my male friend, because his brother was only 35 years old, married with small children, an apartment loan, etc. How this life had collapsed because of melanoma. Now this case was more than four years in the past, but it still hurts him so badly. Then I thought, how will I tell him that I also have melanoma? And what about my sister? How should I tell them? We have already lost one sister to cancer, but this was a long time ago. My sister was ten when she died. I was eight years old then.

An hour had passed since I heard I have a melanoma, and in my mind I have gone through terrible things. I panicked and had the feeling I could not breathe. The

	greatest anxiety I had is because of those close to me. For me it will be easy if I die, but those who stay here – I began to cry – I do not know, did I cry for them or for myself. My two cats looked at me, eyes all round as I sat on floor and cried.
[Cancer aetiology]	[3] <u>I looked towards the window and saw the sun shining, the summer was at its best. I hated the sun, although I had loved it so much before: now I sensed it as my enemy.</u> Although with my inner confusion I realised that melanoma cannot be caused only by the sun. The illness predisposition could be genetic – what about viruses? I easily got herpes on my mouth and erysipelas on my legs. Whatever caused it, the truth is that I have melanoma.
[Talking about cancer to others]	[4] I waited for the call for surgery. I was filled with terrible fear. The call came rather soon. At that time, when I was waiting for access to the hospital, those two weeks were the most terrible period in my life. I could tell neither my son nor my boyfriend – no one – what was wrong with me? <u>I turned really aggressive. I thought: as I shall die I shall act really badly, then no one will miss me when I pass away.</u> They wondered at my behaviour. Until, on the 11 <sup>th</sup> of July, I said that the birthmark on my feet was malignant and tomorrow I must go to hospital. I could not say it was melanoma. I could have told my son about melanoma – but I was afraid of my boyfriend's reaction.
[Suffering alone]	[5] I left the thing hanging in the air. It was the end of July and I went to the central hospital, the department of surgical procedures. I was accepted really well. The main physician came to have an interview with me. He asked if there had been any cancer in my family, had I been a great sunbather, is the (red) colour of my hair natural etc.... I had to give all positive answers. <u>They showed me my bed, I sat on it. It was like a ship going down.</u> I stayed there waiting for the doctors participating in the procedure. The anaesthetist was a middle-aged woman, very friendly. She took a chair and sat down by my bed and told me about spinal anaesthesia. Then a typical surgeon came. He stood by my bed his hairy hands placed on his hips. He was about forty, dark, a bit short but quite interesting looking. He said professionally how the surgery is done. That is, the surgeon will remove tissue from large deep area and take some skin for grafting from the thighs. He was sorry that there will be a deep hole in my leg. Well that was the last thing I cared about at that moment.
[Talking to her son and husband]	[6] After the doctor's visit I had some free time. I was suddenly terribly home sick: I had to get home. So we agreed at the department that I could go home for a night and come again in the morning. The nurses gave me instruction on how I should prepare myself in the evening, and the sleeping pills that I can take if I felt the need. I was at home as though for the last time. In my mind I said goodbye to my son, boyfriend and cats. I called my sister and told her what was happening, and although I was playing everything down, inside I was crying. I had already given up and accepted my destiny. It seemed that people around me accepted it as well; my son and my boyfriend acted as though they did not want to talk about it. Then they said that no wonder you have been so weird, depressed and tight lately. I admitted that I did not know how to tell them about it. <u>I realised how hidden sorrow can harm one's surroundings.</u> I slept well overnight, partly thanks to the sleeping pills, partly because the night before I had been awake, and partly because I had begun to accept the situation.
[In the hospital, patient-doctor communication]	[7] Early in the morning I went back to the department. I felt as though I was having varicose vein surgery. I got an open shirt, went to take a shower, got some pre-medication and after that I was not allowed to rise from my bed – I was waiting for my turn. There was no need to wait long, a young nurse came to my bed. She held a paper in her hand, which she looked at saying now we can go. The way to the surgery hall felt long. I was moved to the surgery table. I got the anaesthesia into my spinal cord, a moment later my feet felt heavy as lead, as though they were frozen. My leg, where the birthmark melanoma was found, was placed on a surgery stand. I felt mystical; I saw my own leg (although it was covered with a green sheet) but I did not feel anything. In the surgery hall the radio was on; I concentrated on listening to it and at the same time exchanged a few words with the anaesthetist.
[Surgery]	[8] The surgery lasted 45 minutes, then I was taken back to the ward. I noticed that the surgeon had made no skin graft – I really did not understand how the surgery had been done. As the operated leg was well covered by bandages, I had to wait until they came to tell me about the surgery. After spinal cord anaesthesia one cannot rise one's head because it might cause a heavy headache. There I was on my back and

	<p>stared at the ceiling. The nurse came to measure my blood pressure. She could not tell why the surgeon had not made any skin transplantation. I was suddenly overwhelmed by fear, helplessness, I thought that the melanoma had already spread so widely that there was nothing that could be done.</p>
[The significance of cancer and personal lifestory]	[9] I was thinking of my life in the past – what have I actually completed? Was there anything still to do – I felt such guilt. Particularly because of the mistakes I had made with my son. What if I die how will he survives?
[Being a patient]	[10] Mealtime came and a helping hand brought the tablet to my table, and even wished me <i>bon appétit</i> ! I had some thinking to do – how to eat – I had to lay on my back and could not raise my head. I thought about calling the nurse, who could help me, but I gave up as I saw they had other things to do. I placed the dish on my chest – it was soup – luckily I found a spoon, otherwise eating would not have been successful. Despite this half of the food was on my chest – I was not even hungry. However, with soup on my chest my expectations of quality of life changed entirely. Now I understood what the most important thing in life is – it is not money, fortune, your position in society – it's love and health.
	[11] I thought about the patient's situation and how humble you feel. I had no self-esteem; I was fully at the mercy of others. It is humiliating to pee in a bedpan, it took hours until I managed it. Although the personnel were friendly, I was still troubled. They could not imagine that I was as helpless and unaware, as all the patients in the room were. That fact that I was a nurse was meaningless. I had a need for additional information, advice, support, for someone to hold my hand at least. They presupposed that I was strong, although I felt that I was falling to pieces on that hospital bed.
[Self-negotiation]	[12] The evening passed, the night came, the next morning arrived. As morning broke, I had to make many decisions. Did I have time to act upon them? I did not know.
[Patient-doctor communication]	[13] The time for the medical examination came. The department doctor, the head physician and the surgeon stood around my bed with enlightened faces. The surgeon told me about the surgery: that the melanoma was in the top layers of tissue, that is to say was graded as Clark 1, and so they had to make only some small incision and could then close the wound directly. The doctor told me that I had been lucky. When I went home I was in good shape. To remove the stitches I had to go the healthcare centre if I did not feel like doing it myself.
[Post-recovery health condition]	[14] The melanoma checks take place in healthcare centre, at first every six months, when they take a lung X-ray. I have been to these check-ups twice but there has been nothing new. My condition is excellent.
[Concerns about her grown up son]	[15] The son, about whom I feel so much guilt, got alcohol psychosis in autumn 1993, which put him in hospital. This was a terrible thing for me. I thought that my melanoma is nothing compared to you losing your mind. They told me that my son had been really worried about me. This made him use more alcohol in order to escape reality.
[The significance of the help offered by society]	[16] I totally forgot about myself. I began to follow how psychiatric care is given today. I saw many mistakes. As a result, I had to develop myself. I applied for a place on a course to learn psychiatric care. At the moment I study. I have a lot to do, both on the somatic as well as the psychiatric side. My son is out of hospital and goes to continuation treatments at the psychiatric unit as well as the AA-clinic. I pray that my son has strength, that he will manage in life. Otherwise, my own life is really good.

